Effectiveness of assertive community treatment in early psychosis

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Effectiveness of Assertive Community Treatment in Early Psychosis

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EFFECTIVINESS OF ASSERTIVE COMMUNITY TREATMENT

IN EARLY PSYCHOSIS

Effectiveness of Assertive Community Treatment in Early Psychosis

De effectiviteit van Assertive Community Treatment in vroeg-psychosezorg

PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Tilburg,
op gezag van de rector magnificus, prof. dr. Ph. Eijlander,
in het openbaar te verdedigen ten overstaan van
een door het college voor promoties aangewezen commissie
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[Assertive Community Treatment for patients with a first-episode psychosis. Model fidelity and specific adaptations for a specific target group. Dutch Journal of Psychiatry 49 (2007) 11, 789-798.]

- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. Model fidelity of Assertive Community Treatment for clients with first-episode psychosis: a target group-specific application. Community Mental Health Journal, 2008.

Chapter 4

- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. Cliënten als ervaringsdeskundig interviewer in wetenschappelijk onderzoek, De betekenis voor de kwaliteit van de verzamelde data en het herstel proces van de interviewers. Tijdschrift voor Rehabilitatie, september 2008.

[Client involvement in mental health research: effects on quality of data and on the recovery process of the interviewers.Dutch Journal of Rehabilitation, September 2008.]

- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. Client involvement in mental health research: effects on quality of data and course of the interviews. Submitted, June 2008.

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- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. Effectiveness of ACT versus Care as Usual in early psychosis: results of a two-year quasi-experimental outcome study. Submitted, December 2008.

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- Verhaegh, M.J.M., Dietvorst, I.A.R., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. Cost-effectiveness of Assertive Community Treatment versus Care as Usual for young persons suffering from early psychosis. Submitted, November 2008.

Presentations

- Verhaegh, G. INVOLVE, 4th National Conference "People at the Heart of Research". Congress participation "Client involvement".
  Nottingham, UK: November 2004.

- Verhaegh, G. Assertive Community Treatment and First-episode Psychosis. Poster presentation: World Congress of Early Psychosis (IEPA) "Beyond the Crossroads!"
  Birmingham, UK: October 2006.

- Verhaegh, G. ACT en eerste psychose. Lezing Kenniscarroussel GGzE.
  Eindhoven: februari 2007.

- Verhaegh, G., Roks, P.J. & Kroon, H. Tussentijdse data uit een quasi- experimentele studie waarin ACT aangeboden aan mensen met een 1e psychose vergeleken wordt met Care as Usual. Workshop Voorjaarscongres Nederlandse Vereniging voor Psychiatrie.
  Maastricht: april 2007.

- Verhaegh, G. Ervaringsdeskundigheid en onderzoek. Lezing Zorgsalon Tranzo.
  Tilburg: mei 2007.

- Verhaegh, G., Roks, P.J. & Kroon, H. Tussentijdse resultaten uit een quasi-experimentele studie van ontwikkeling van de experimentele groep cliënten die ACT aangeboden kregen na twee jaar behandeling. Workshop Voorjaarscongres Nederlandse Vereniging voor Psychiatrie.
  Amsterdam: april 2008.

- Verhaegh, G. Intern referaat voor leden van de Nederlandse Vereniging voor Sociale Psychiatrie.
  Eindhoven, september 2008.

- Verhaegh, G. Cost-effectiveness of Assertive Community Treatment in Early Psychosis.
  Presentation: World Congress of Early Psychosis (IEPA).
  Melbourne, Australia: October 2008.

CHAPTER 1

INTRODUCTION

In this chapter we give an overview of recent developments in early psychosis and what treatments have shown the most adequate over the last decennia. We focus in this perspective on one of the most studied and most applied evidence-based practice in mental healthcare (Dixon, 2000; Rosen, Mueser, & Teesson, 2007). Consequently we address how Assertive Community Treatment (ACT) is applied in early psychosis. This part is followed by the research questions of this study. We start to illuminate the importance of a high quality early psychosis treatment.

There is lots to prevent and much to lose

Young people confronted with a first-episode psychosis often recall this event as being traumatic. Everything changes, everything is confusing and frightening. It feels as if control, certainties and apparent normalities have been lost. One's life is suddenly upside down and friends, colleagues and carers act differently. Feelings are unfamiliar and there is lack of energy, power, confidence and self-esteem. One patient who lost her husband due to an accident spoke about this terrible event. With tears in her eyes she also said: "*... but having a psychosis is even more devastating*".

When young people experience their first psychosis there is need to prevent the loss of many important roles and relationships. People have family, colleagues, friends and many other social roles and functions, and derive much self-esteem from these various roles and positions. Patients often tell about the terrible situation they experienced when they were admitted to a psychiatric hospital, and the impact this had on their awareness of having responsibility for their own life. We all know (or can imagine) how quickly the phenomenon of 'hospitalization' occurs when one is even temporarily admitted to a general hospital; hours and days pass, everything happens automatically and individual responsibility is lost. Suddenly one is no longer an adult person but a 'patient', such as described by Goffman in the 1960s in his historical work *'Asylums'*. In other words, there is a lot to prevent and much to lose. But how can this be achieved?

The initial ideas about re-designing the early psychosis program emerged when professionals in Eindhoven realized that often years had passed before patients were transferred to a specialized psychosis service. For first-episode patients, modern insights emphasize the importance of a short period between the appearance of the first positive symptoms and specialized treatment. Early detection and early intervention were magic words.

An additional trigger for a renewed design of early psychosis treatment emerged from the long-term mental healthcare for psychotic patients. Here, ACT was a well-accepted evidence-based practice that also had proved to be (cost-)effective. In Eindhoven, the professionals

questioned whether this treatment model could also be useful for the target group of persons suffering from early psychosis. Characteristics such as 'pro-active' seemed to meet the demand of early intervention. The multidisciplinary team approach and 'assertive outreach' might help to prevent the loss of social roles and positions.

Developments in early psychosis

Psychosis in general, and the most well-known subtype schizophrenia in particular, is considered a severe and often long-lasting psychiatric illness. However, the illness has many different manifestations that can range from "... *mildly passing by*" up to "... *a lifelong and devastating illness*". Psychoses appear in all varieties and degrees of intensity. Everyone can recognise a full-blown exposure of psychosis within a second.

Since Bleuler and Kreapelin (Hoenig, J., 1983), many professionals and scientists have explored and described the phenomenon of psychosis and tried to find new ways to treat patients successfully. From the beginning, psychosis (schizophrenia) was considered to be an illness that could not be totally cured without some lingering symptoms. Treatment took place by means of "stepped care". This means that (in the first instance) the most effective, least burdensome, cheapest and shortest way of treatment possible (given the nature and gravity of the situation) will be offered. When this intervention proves to be insufficiently effective or inadequate, a more intensive intervention is selected (Meeuwissen, & Weeghel, 2003). This often meant that, after years of unsuccessful treatment, patients receive intensive clinical treatment for the rest of their lives. At this moment, many prominent scientists (Pelosi, & Birchwood, 2003; McGorry, Purcell, Hickie, & Jorm, 2007) strongly recommend intensive treatment at the (very) early phases of psychosis to prevent delay of adequate treatment. McGorry, et al. (2007) call early intervention "a best buy", referring to enhancement of short and long-term outcome and, thereby, preventing resources and money being expended on years of inpatient treatment. The treatment of psychosis has made a shift to early detection and intervention, from a focus on the disease to the recovery of vulnerable persons, and exploring opportunities for a cure instead of emphasizing illness and its related shortcomings. In 1998, Birchwood wrote: *"The potential benefits of early intervention include: reduced morbidity, more rapid recovery, better prognosis, preservation of social skills, family and social supports, and decreased need for hospitalization* (Birchwood, et al., 1998).

Modern mental healthcare in first-episode psychosis follows an illness phase-specific program of care delivery (IEPA writing group, 2005). The first phase of psychosis is the pre-psychotic phase and consists of two sub-phases, the premorbid phase (when the patient shows no emotional, cognitive and behavioural impairments) and the prodromal phase (when the first signs and brief symptoms [Brief Limited Intermittent Psychotic Symptoms, BLIPS] appear).

The second phase starts with the first psychosis. This is when patients experience positive symptoms (e.g. hallucinations and/or delusions) and need intensive (crisis) treatment. The third phase is called the 'Recovery' period (6-18 months after the first psychosis) and the 'Critical' period (first 3-5 years after the first episode of psychosis). This third phase covers at least the critical period, and the aim is to enable the patient to recover and regain social roles and capacities. The duration of this phase varies considerably and can last for decennia. An important finding is that recovery from psychosis never stops; there are always new possibilities and opportunities to enhance function and improve quality of life (Farkas, 2005; Salyers, 2007). Beside caring for and healing the illness, professionals aim for an early intervention, preferably starting as soon as possible after the first appearance of positive symptoms up to providing the first adequate treatment (Duration of Untreated Psychosis, DUP). Adequate treatment in the critical period is important because it is associated with a better course of the illness and functional recovery. Adequate treatment in the critical period focuses on all aspects of living, e.g. social functioning, relationships, relatives, work, school, leisure time, and somatic issues with (preferably) evidence-based interventions, such as: Supported Employment (e.g. Individual Placement and Support), Supported Education, Cognitive Behavioural Treatment, Double Diagnosis services, Family treatment, pharmacotherapy, and ACT (Edwards, Harris, & Bapat, 2005; Addington, 2006; Drake, Essock, McFarlane, 1997, Shaner, et al., 2001).

Assertive Community Treatment

ACT is the most studied and most applied evidence-based practice in mental healthcare (Dixon, 2000; Rosen, Mueser, & Teesson, 2007). In 1971, Ludwig, Marx and Test at the Mental Health Institute in Madison (Wisconsin, USA) founded ACT. Based on their new vision they created an innovative program called the "training in community living model". It was developed for Severe Mentally Ill (SMI) patients who, until then, were generally living in a mental hospital. The program started from a specialized hospital unit that evaluated psychosocial techniques for the target group of SMI patients. After some time, when Ludwig was replaced by Stein, the new trio realized that success would only be possible when they functioned from a different location. Thus, they decided to move away from the mental hospital into the community. Marx, Test and Stein are considered the creators of the most important new mental healthcare program in the last 30 years. The "training in community living program", nowadays called "Assertive Community Treatment", received the Gold Achievement Award from the Hospital and Community Psychiatry Service of the American Psychiatric Association in 1974. The main target of the program was to enable patients to regain their dignity, improve their quality of life and social skills, in order to return to the community. Patients were trained to cope with the problems of living in the society. The team members themselves were re-educated and used a variety of community resources such as work, leisure activities, local services, communication and housing facilities. From the beginning the three founders of the program investigated the

outcome of their new treatment by comparing the community group with a control group. Their first finding was that patients succeeded in their goal to live in the community. After only 5 months hospitalization rates decreased and participants in the experimental group showed better functioning on the level of symptoms, employment, social relationships, and subjective life satisfaction. The achievement had no negative influence on the community or family burden, i.e. patients did not improve their level of functioning at the expense of relatives or other citizens. Marx, Test and Stein also performed a cost-benefit analysis and found an advantage for the training of the "living in the community program"; the costs were higher, but the treatment outcome was much better. They concluded that, by the end, the program showed a positive cost-benefit balance (Stein, Test, & Marx, 1975). During the following years the program spread over several locations in the USA and other parts of the world. The replications of the program were successful. In all studies ACT showed the same positive outcome, but on the condition that there was high fidelity to the original program (i.e. as in the Institute in Madison) on comparable outcome measures (Thornicroft, 2000; Stein, 2001). To measure the fidelity of the implemented program, fidelity scales were developed. The best known and most used scale is the Dartmouth Assertive Community Treatment Scale (DACTS). The DACTS (Teague, Bond, & Drake, 1998) consists of 28 items, each rated on a 5-point behaviourally-anchored scale with a score of 4.2 or more indicating 'full implementation', 3.0 to 4.2 indicating 'moderate implementation', and 1.0 to 3.0 indicating a 'low degree of implementation'.
Once the "living in the community program" had been implemented it received different names (e.g. intensive or assertive outreach team, intensive case management), different applications (for different target groups and in rural surroundings) and was adapted pragmatically, in spite of the findings that showed an association between the fidelity level of the program and the outcome of the provided services (McHugo, Drake, Teague, & Xie, 1999).

Typical features of the ACT model (see Chapter 3 for details; Teague, Bond, & Drake, 1998; Test, & Stein, 2001) are:

1. The attitude of the professionals is pro-active and assertive.
   Professionals acting assertively do not agree when patients refuse to cooperate, or are not compliant to treatment or medication, or tend to reject the offered services. They act pro-actively and try to prevent problems in work, social environment and relationships. Professionals initiate activities and make use of opportunities that occur. They are focused on early signs and symptoms of psychosis.
2. Treatment takes place in the community.
   One of the first and most emphasized merits of the 'living in the community' treatment model was, and still is, preventing patients from hospitalisation (Dixon, 2000). From the beginning the founders took community care as a leading premise; professionals' interventions preferably take place within the community, at home where the patients live, at their

work or school, and in their natural environment. Their social training activities also take place in daily life, to prevent the generally acknowledged disadvantage of the non-generalizing therapy effects of many mental health interventions that were practiced under treatment conditions.

3. The multidisciplinary team is responsible for a group of patients.
   An ACT team has a shared case load; each team member has the responsibility for the total group of patients. The discipline-related responsibilities overlap. Every professional has a broad scope of activities that goes beyond their own personal responsibility.
4. The team delivers all the required services.
   ACT is often considered to be an organisational model; a structure that prescribes how to organize mental healthcare. However, from the beginning (Ludwig), Marx, Test and Stein intended to develop a community-based alternative for hospital treatment, and developed many types of social training interventions to help patients cope with living in society (Stein, Test, & Marx, 1975). The DACTS (Teague, et al., 1998) also reflects this intention, it consists of items and subscales that emphasise the importance of a well- organized model and combines it with integrated evidence-based interventions, e.g. involving the support system, and vocational and substance abuse expertise.
5. Time-unlimited services.
   Initially ACT was developed for severe mentally ill patients and subsequently one of its characteristics was to provide time-unlimited services. When ACT was provided to the target group patients suffering from first-episode psychoses this DACTS item was often discussed. Professionals argued that it would be too expensive and not necessary. Others argued that it could be time-limited but not shorter than the critical period (3-5 years) after appearance of the first positive symptoms. In daily practice, managers and professionals must decide how long treatment period will be continued. Examples include: Stein & Test (1975) (stopped after 14 months), and OPUS (stopped after 2 years) (Bertelsen, 2008). In those latter projects it turned out that the gains more or less disappeared shortly after treatment stopped. A solution has not yet been found, but evidence for prolonged treatment (up to at least 5 years) is still accumulating.

Santos and Stein redefined the description of ACT in 1998 and made clear that ACT is not only a organizational model: *"Assertive Community Treatment is best conceptualized as a service delivery vehicle or system designed to furnish the latest, most effective and efficient treatments, rehabilitation, and support services conveniently as an integrated package. It serves as the fixed point of responsibility for providing services to a group of individuals with severe and persistent mental illness identified as needing ACT services to achieve any of several desired outcomes (e.g., reduced use of 'revolving door' hospital services, increased quality and stability of community living, normalizing activities of daily living such as competitive employment). Services are not*

time-limited or sequenced. Service intensity varies with changes in desired outcomes. Services are provided for as long as needed" (Stein, & Santos, 1998).

Several countries (also outside the USA) also found, in most cases, similar outcomes. In their review of 75 studies, Mueser, Bond, Drake, & Resnick (1998) reported that several types of intensive case management (such as intensive outreach and ACT) reduces the use of hospital days, improves housing stability and shows a moderate effect on symptomatology and quality of life. Little effect was found on social functioning, arrests and time spent in jail, and vocational functioning.

In 1998, Marshall, & Lockwood performed a review on results of ACT on patients with severe mental illnesses. They compared the outcome of ACT with three alternative service models. Patients receiving ACT were more likely to remain in contact with services than those receiving standard community care, were less likely to be admitted to hospital, and made less use of hospital beds than those receiving standard community care. Also on clinical and social outcomes, significant differences were found between ACT and standard community care in favour of ACT, e.g. on social adjustment, employment, and patient satisfaction with their treatment. No differences between the two treatments were found for mental health state and social functioning. ACT showed to be more cost-effective due to less hospital usage. However, if all costs would be included the difference was no longer significant. ACT patients were not more compliant to their treatment than those receiving hospital-based rehabilitation services. Patients receiving ACT were significantly less often admitted to hospital than those receiving hospital-based rehabilitation, and significantly more often lived independently. Patients allocated to ACT consistently spent fewer days in hospital than those given case management. The cost of hospital care was more expensive for case management, but when other costs were taken into account the cost difference disappeared.

Burns, Fioritti, Holloway, Malm, & Rössler (2001) reported on case management (heterogeneous forms of community care, some of them comparable to ACT) in Europe. Although it is difficult to compare hybrid forms of healthcare models, they concluded that in general the results of case management in Sweden, Germany and Italy were more hopeful than the treatment outcome of intensive outreach as shown in the UK (UK700, 1999). When compared to other forms of case management, ACT showed better results on different kinds of outcome measures (reduction in hospitalization, improvement in quality of life, small gains on social and clinical functioning) but not to the same extent as found in the USA (Burns, et al., 2001).

ACT and early psychosis

From the 1970s, ACT was applied to the severe mentally ill patient and, as described above, several applications were made during the following decennia (Dixon, 2000). Since the 1980s several themes have emerged in relation to ACT, including fidelity, cost-effectiveness, adaptations and integrations (ACT and recovery), and new target groups (e.g. patients suffering from personality disorders, substance abuse and first psychosis) (Burns, et al., 2001; Drake, & Deegan 2008; Salyers, & Tsemberis, 2007; McDonel, Bond, & Salyers, et al., 1997).

One of the variations is applying ACT to patients suffering from early psychosis. In England the political acknowledgement of the limitations of service provision to First-episode Psychosis (FEP) clients within generic mental healthcare service systems (Yung, Organ, & Harris, 2003) was the starting point of 50 early intervention services for FEP (Dept. of Health, UK, 2000). In Australia the Victorian state government funded a state-wide Early Intervention Worker Initiative (Dept. of Human Services, 2000).
The new area of interest, early treatment of patients suffering from psychosis, addressed new treatment insights such as the correlation between the Duration of Untreated Psychosis (DUP) and the outcome of the provided treatment (the earlier the treatment was provided, the better the treatment prognosis) and the concept of the critical period (adequate treatment in the first 3-5 years predicts better short and long-term outcome).
From this viewpoint, the pro-active and assertive attitude, and intensive multidisciplinary treatment of ACT, were highly promising features. The shift from "curing patients" to "recovery of vulnerable people" was also a good match with the integrated treatment concept of ACT where a multi-disciplinary team looked after all aspects of (social) recovery. After applying the model to the new target group the provided services were tailored to the needs of these patients and their carers.

The most well-known (international) initiatives where ACT was applied to young patients suffering from a first psychosis are located in England (Lambeth Early Onset [LEO], Outreach and Support in South London [OASIS] and Croydon Outreach and Assertive Support Team [COAST] in London; Denmark [OPUS project], Norway [TIPS project], and Australia (Early Psychosis Prevention and Intervention Centre [EPPIC] in Victoria Melbourne). Presented below is a brief overview of these projects and their treatment findings, followed by an illumination of additional topics related to outcomes measures.

England

In England over 100 early intervention services were initiated in the last decade. All services intend to meet the goals of the Early Psychosis Declaration, the National Health Service Plan and the Policy Implementation Guide (Power, et al., 2007).

Lambeth Early Outreach (LEO) and Outreach and Support in South London (OASIS), two of the early starters in the new early psychosis policy, provide a range of services with the aim to reduce the Duration of Untreated Psychosis/delay in treatment provision, provide evidence-based care, and reduce the distress and burden of carers during the critical period (first 2 years) of the illness. The LEO and OASIS service consists of four teams working together in a broader network of primary and secondary mental healthcare facilities. Each of the teams focuses on one of the four phases of recovery and provides specialized services. OASIS focuses on ultra-high risk (phase 1: overwhelmed by the disability), the LEO-Crisis Assessment Team (CAT) on patients in their crisis phase (phase 2: struggle with the disability), the LEO Unit is an inpatient treatment service (phase 3: living with the ability), and the LEO Community team delivers recovery services (phase 4: living beyond the disability) (Spaniol, Wewiorski, 2000).
Aims of the services are to improve clinical and social outcomes through early identification, assessment, treatment and support of people with psychosis using a multi-disciplinary framework. The service aims to engage clients (aged 16-35 years) at the earliest possible opportunity following their first or second presentation to mental healthcare services. At this stage vital links with families, relatives and social networks are more likely to be intact. The LEO and OASIS teams work assertively to strengthen and extend these links and re-establish those which have broken down. In 2007 Power, et al. published the effects of the LEO-CAT team. They train general practitioners in detecting early psychosis. This resulted in improved detection and referral rates of first- episode psychosis patients. In this way the early detection team of LEO-CAT reduced the long delays in initial assessment and treatment. The training only had an impact on the later phases of the DUP where signs and symptoms are more clearly recognizable (Power, et al., 2007). Craig, et al. (2004) reported the results of the LEO Community team. They found less re-admissions and a better adherence to treatment in the Assertive Early Outreach group versus the group who received standard care. In 2006 Garety, et al. presented more results of the LEO Community team. After 18 months of treatment they found better results for the experimental group treated in the LEO setting: better outcome on symptoms (not significant), more social relationships, more vocational activities, better quality of life, better global functioning and better compliance to medication. In addition the above-mentioned achievements were also found after 18 months (more contacts with services and less hospital use).

The Croydon Outreach and Assertive Support Team (COAST) in the south of London serves patients with first-episode psychosis up to 5 years after the first episode. They provide a range of medical, psychological and vocational services tailored to the individual needs. After one year they found only a few results in favour of the COAST services. Overall both groups improved over the one-year period, but not to the same extent. The COAST group achieved better overall functioning, but the difference was not significant. There was less (not significant) usage of

beds in the COAST group versus the standard care group and, thereby, less costs were incurred for the COAST group. In the present research group no differences were found for social and vocational functioning, or for clinical measures (Kuipers, et al., 2004).

Denmark

The OPUS study in Denmark is a large randomised clinical trial that compared integrated treatment with standard treatment provided to patients with first-episode psychosis. At the start, their goal was to reduce the DUP and enhance the course of the illness (Jorgenson, 2000). The project offered the integrated treatment (ACT-like model, fidelity rate of 70%, paying special attention to family treatment and in vivo social skill training) for 2 years, and afterwards shifted the experimental group to standard care.

After 1 and 2 years the experimental group showed significantly better outcomes on positive and negative symptoms (moreover the experimental group had significantly lower doses of anti-psychotics), had less co-morbid substance abuse, better adherence to treatment, and patients were more satisfied with their treatment than members of the control group. In the first year the experimental group used less inpatient care (62 bed-days versus 79 bed-days). In the second year the difference was no longer significant (89 days versus 114 days in the control group). The treatment outcome for housing, depression, and suicidal behaviour and ideation was less successful. In the first year many more patients in integrated treatment lived independently; in the second year this difference had disappeared (Petersen, et al., 2005). Patients from both groups scored almost the same on: "suicide attempts", "suicidal thoughts" and "thoughts that life is not worth living".

After 5 years the clinical outcome improvements achieved in the first 2 years of integrated treatment had disappeared; both groups showed the same functional outcome. Results on symptoms, Global Assessment of Functioning (GAF) scores, substance abuse and medication doses had disappeared. Also, there were no differences on suicidal behaviour or depression. The only exception in favour of the experimental group (over a 5-year period) was better functioning in supported housing and less use of hospital beds. The study showed equal proportions (experimental group 39% versus 41% of the control group) of patients that had a job or went to school.

Norway

First-episode psychosis policy and treatment in Norway focuses on effects of shortening the DUP and consequently enhancing the course of the psychosis. A specialized part of the Norwegian TIPS project consists of early detection teams (DTs) that provide early detection strategies (psycho-education, alternative inclusion strategies). The DTs included younger, mostly male, and more often substance-abusing patients in a worse mental condition (lower GAF scores and longer DUP scores) compared with patients included following the usual referral procedure.

After 2 years of treatment the baseline differences had disappeared. The DTs then reached another part of the group, i.e. those with a worse prognosis, and succeeded in raising these patients to a similar functional recovery level. The other part of the strategy to reduce the DUP was information campaigns. Professionals provided information about early psychosis, early signs and symptoms, recovery courses, treatment possibilities and stigmatisation processes. Although the TIPS project resulted in a reduction of the DUP, the precise contribution of both interventions to the results remains unclear. Efforts in other countries to shorten the DUP by using information campaigns (OPUS and EPPIC) were disappointing and showed no significant outcome (Johannessen, 2007).

Australia

The Early Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne aims to provide a model for the optimal management of first-episode psychosis. EPPIC began operation in 1992, designed to offer a 'real world' model for the management of first-episode psychosis for young people aged 16-30 years. Its catchment area covers a population of 800,000, including a high percentage of recent immigrants, low-income families and unemployed. Services through

EPPIC are provided for up to 2 years and include a comprehensive range of community-based and in-patient programming (Power, et al., 1998). EPPIC aims to minimize hospital use, utilize as low a dose of neuroleptics as is effective, and minimize the use of in-patient facilities. Some of the program components are: Outpatient Case Management program, Family Work, Cognitive Oriented Psychotherapy, Treatment Resistance Early Assessment Team, Systematic Treatment of Persistent Positive Symptoms, and brief cognitive therapy for those at extreme risk of suicide.

The programs provide psycho-education, cognitively-oriented psychotherapy, treatment for cannabis use, suicide and relapse prevention, case management, and pharmacotherapy (second-generation antipsychotic medications).

The results of a comparison of a sample of EPPIC clients with a pre-EPPIC sample indicates that at 12 months, the EPPIC program evidenced reduced hospital stays in frequency and duration, reduced levels of negative symptoms, lower doses of neuroleptics and improved quality of life scores (McGorry, et al., 1996).

Measurements at 3 months indicate that the proportion of clients hospitalized was reduced from 84% to 63%; number of inpatient days was decreased from a mean of 50 to 18 days; and neuroleptic dosages were reduced without compromising clinical outcomes. The more recent results provide evidence that with proper assessment and treatment, over 30% of people with first-episode psychosis can remain in the community during the acute phase of illness. In

addition, through community education efforts, the proportion of referrals from family and friends increased from 10% in the first 6 months of operation to 25% in the second 6 months. Similarly, GP referrals increased from 5% to 10% (Edwards, et al., 1998).

Additional topics related to outcome measures

Substance abuse

Co-morbid substance abuse in early psychosis is a major topic in mental health care. It is highly prevalent in first-episode psychosis with rates ranging from 6% to 44% for drugs and 3% to 35% for alcohol (Petersen, 2007). Substance abuse is associated with: exacerbated psychiatric disturbances which consequently profoundly affect the course and outcome of schizophrenia, leading to more psychotic symptoms, to poorer outcome in rates of employment and treatment compliance, to homelessness, to more and earlier relapses, and to greater service utilization and costs. The negative outcome associated with substance abuse co-occurring with serious mental illness, and the acknowledged difficulties in treating this group of patients make it important to focus on early intervention in this group.

Petersen, et al. (2007) studied a group of 547 Danish patients who had first-episode schizophrenia-spectrum disorders and who abused substances. Subjects were randomly assigned to ACT (with family involvement and social skills training components) or to standard treatment at a community mental health clinic.

Subjects were evaluated 2 years after treatment entry, and 17.3% of the clients in ACT met criteria for a substance abuse diagnosis compared to 20.7% of clients in standard treatment. Clients who received the ACT treatment also showed significantly lower levels of negative and disorganized symptoms compared with standard treatment. Despite the reduction of substance abusers, the expectations about outcome on misuse of drugs and alcohol were much more optimistic. Researchers concluded that co-morbid substance abuse is difficult to reduce.

Waldron, Turner, & Clin (2008) synthesized findings from 17 studies since 1998 regarding evaluation of outpatient treatments for adolescent substance abuse. These studies represented systematic design advances in adolescent clinical trial science. The research examined 46 different intervention conditions with a total sample of 2,307 adolescents. Three treatment approaches, multidimensional family therapy, functional family therapy, and group CBT emerged as well-established models for substance abuse treatment. However, a number of other models are probably efficacious, and none of the treatment approaches appeared to be clearly superior to any others in terms of treatment effectiveness for adolescent substance abuse.

Medication

"Start low, go slow" is a statement from the IEPA guideline. It means that antipsychotic medication is important but should be started using low doses and titrating upwards (raise doses) must be done very slowly. Great attention should be paid to side-effects because of its correlation with compliance (International Early Psychosis Association (2005). In guidelines there is a broad consensus about the preferred pharmacotherapy. Atypical antipsychotic (second generation) medications are undoubtedly preferable to typical antipsychotic medicines due to less side-effects. All early psychosis studies describe a medication policy based on the low dose principle and second generation as first choice (Petersen, 2007).

Supported employment and supported education

Attention to supported employment and supported education is a main issue in most guidelines dealing with modern early psychosis treatment. There is convincing evidence of significantly better outcomes when applying supported employment or education interventions, such as Individual Placement and Support (Collins, et al. 1998; Mueser, Salyers, & Mueser, 2001). Supported education correlates with better employment rates in that finishing a study is an important predictive factor for obtaining a job.

To enhance the outcome of supported education "social support" is the most effective intervention. Social support has to be provided by an individual who helps choose the right education, attend a study, and arrange financial resources. Furthermore, patients need individual support to achieve a balanced day/study structure, in order to learn study skills (Kroon, Van Erp, 2002). Supported Employment proved to be more successful than standard treatment in helping patients get a paid job. In the USA, the strategy "Training and coaching on the job" was found to be successful (Dutch Guideline for Schizophrenia, 2005; Collins, et al., 1998; Mueser, et al., 2001)

Carers' burden

For patients with first-episode psychosis it is important to have a social network that cares about them. A social network is essential to give support to the patient, create a safe environment and prevent hospitalisation.

Dixon (2000) highlighted some important issues concerning family involvement and treatment of first-episode psychosis. First of all, the importance of involving the family in the treatment of their relatives must be acknowledged. This issue has been confirmed by many authors (IEPA writing group, 2005; Roick, et al., 2007; Cuijpers, & Stam, 2000; Hazel, et al., 2004). Another issue concerns early detection and early treatment. Before a patient becomes connected to mental healthcare, in the prodromal phase, the carers have already encountered stress and various concerns. To prevent carers' burden, early detection (short DUP) and early intervention is important. Interventions that proved to be successful are Family psycho-education

(Dixon's third issue) and Multi-family groups (Dixon, 2000; Cuijpers, & Stam, 2000; Hazel, et al., 2004). The OPUS study describes psycho-educational family group therapy where staff, carers and patients discuss problems, find solutions and practice them in vivo. In the follow-up meeting the experiences are further discussed (Jeppesen, 2005). The fourth issue is a plea for tailored attention to the family, because "not all families are the same". This point is made to enhance the compliance to the interventions. A final issue addressed by Dixon is the provision of good medication. Carers indicated that they experienced stress from living with a relative who suffered from positive symptoms. Carers' burden is associated with the consequences of experiencing distress related to patients with mental disorders resulting in disturbed behaviour, a change in social role performance, and an adverse effect on others (Jeppesen, et al., 2005). In the same study Jeppesen, et al. state that the likelihood of carers enhancing the treatment is associated with older age of the patients, belonging to an ethnic group, less education, and worse functioning of the patient prior to the first-episode psychosis (Roick, et al., 2007).

Suicidal behaviour and suicidal ideation

Suicidal behaviour and suicidal ideation are correlated to psychiatric diagnosis such as psychotic disorders. Prior to their first-episode psychosis (prodromal phase) about 10% of all patients attempted suicide and up to 22% showed suicidal ideation. After 4 years 18% of all patient with early psychoses attempted suicide and 3% completed suicide. The high prevalence figures challenge professionals to intervene, especially in the very early phase of psychosis. Efforts to reduce the DUP period are therefore very important (Clarke, 2006).

Research findings show correlations between suicidal ideation, female gender, prior attempts, depression, hopelessness and poor prognosis, and active suicidal behaviour. These risk factors should be the starting point of psychiatric interventions. Interventions showing positive results are CBT (Haddock, & Lewis, 2005) and ACT (Nordentoft, 2002).

ACT and early psychosis in GGz Eindhoven

The Netherlands lacked experience with the ACT treatment model for this target group and initially ACT professionals based most of their decisions on the results described for other countries (Power, McGuire, Iacoponi, Garety, et al., 2007; Jeppesen, Petersen, Thorup, Abel, et al., 2005; Nordentoft, Jeppesen, & Petersen, 2003; MCGorry, 2004). Because ACT was new for this particular target group, the ACT team in Eindhoven decided to start ACT as originally prescribed in order to establish whether ACT would be effective for this specific group. From the beginning fidelity with ACT was measured using the DACTS (Teague, Bond, & Drake, 1998).

According to incidence data of early psychosis, care should be provided to male patients aged 15 to 25 years, and to female patients aged 25 to 35 years (Häffner, 1994; Yung, & McGorry, 1996).

The ACT-team preferred to use the term 'early psychosis' for the mental healthcare of this target group. The label 'first-episode psychosis' over-emphasizes the first episode and places less emphasis on the important subsequent phases of recovery. In this early phase, much can be achieved in terms of secondary and tertiary prevention of the disease. Another reason for calling this type of care 'early psychosis healthcare' comes from studies on the Duration of Untreated Psychosis (DUP). According to those studies it should perhaps be called 'very-early psychosis healthcare'. Those studies provide increasing evidence that much damage can be prevented by early detection and fast intervention.

Another initial decision was to include all different diagnoses within the wide spectrum of psychosis, and the ACT team aimed to treat all the included patients for 3 years. This decision was made because ACT professionals believe that there is no measurement instrument that has valid prescriptive features that can differentiate between patients with a 'once-only single psychosis' and patients who will experience more psychotic episodes.

Within the specific ACT organisational context, the ACT team intends to provide evidence-based services based on the best available knowledge. When possible, evidence-based services are provided and, if not available, professionals rely on best practices and their own experience. An important starting point is the recovery process of the client. All team members are experienced and are trained in the Boston Rehabilitation (Center for Psychiatric Rehabilitation, 2008) and Rehab '92 methodology. The team meets the needs of the clients and their carers, and contributes to their recovery process using specific communication techniques and rehabilitation-based interventions (readiness assessment, Liberman modules). Examples of shared values are that the services and staff are easily accessible, and that the communication between team members, as well as between professionals and clients/carers, is on an equal basis.

Research questions

In Mental Healthcare Eindhoven developing early psychosis treatment of an excellent quality was a big challenge and was surrounded by mixed feelings and many questions. Nevertheless, based on ambition, insights from literature and successes of foreign initiatives, the ACT team in Eindhoven started providing full implemented ACT for the target group of patients suffering from early psychoses.

To get answers on the posed questions, there was decided to guide the project by an effect study that addresses the following questions:

...does Assertive Community Treatment, provided to clients suffering from early psychoses during their critical period, show significantly better treatment effects regarding quality of life, psychosocial functioning, and psychopathology, compared to the effects of Care as Usual provided to a similar group of patients, also with regard to the costs incurred with both forms of treatment?

To answer these points the following questions (derived from the main research question) were addressed:

- Does ACT meet the demands of the target group and how does the model get a target group- specific application?
- Over a two-year treatment period, what effect does ACT have on patients who suffer from early psychoses compared to a similar group of clients who received CAU?
- Over a two-year period, what effect (based on 3 outcome areas) does ACT have on the recovery process of patients who suffer from early psychoses?
- Is ACT a cost-effective treatment model compared with CAU?

In this study we additionally addressed the following research question that emerged from special interest, and concerns a particular way of data collection using client interviewers:

- What influence do client interviewers have on the quality of the collected data and on the course of the interviews?

Outline of this thesis

The previous sections describe the background and objectives of the work presented in this thesis and the research questions addressed.

Chapter 2 presents an overview of the study design, describes the characteristics of the experimental and control groups, and the treatment provided. The inclusion criteria are presented, and information is given about the two treatment conditions, the outcome measures, and the drop-out rates.

Chapter 3 focuses on the experimental treatment condition: i.e. how to apply the ACT model to the specific demands of the patients and carers of the target group under study.

Chapter 4 presents a special item of this study that is related to better quality of the collected data. This arose from the experience and insights we gained from a congress on client involvement in research (INVOLVE, 2004). Based on those factors, we randomly assigned respondents to a professional or to a peer reviewer. Either the professional or the peer reviewer interviewed

the patient and completed questionnaires related to the patient's quality of life. The process and results of this specific investigation are described.

Chapters 5 and 6 present the main results of our research. Chapter 5 focuses on the differences in outcome between the two treatment groups over a two-year period.

Chapter 6 describes the recovery process of members of the ACT group who completed several questionnaires concerning their quality of life, clinical functioning, and social functioning.

Chapter 7 examines the cost-effectiveness of ACT compared with CAU. This investigation calculated costs from the bottom-up and related these to the outcome effects of the two treatment conditions.

Finally, in **Chapter 8**, we present the result and the limitations, discuss the findings, and make recommendations for further study and development.

References

- Addington, J. (2006). Cognitive-Behavioral Therapy for Individuals Recovery from a First Episode Psychosis. *J Contemp Psychother*; 36 (1), 43-49.
- Bertelsen, M., Jeppesen, P., Petersen, L., Thorup, A., Øhlenschlæger, J., le Quach, P., et al. (2008). Five-Year Follow-up of a Randomized Multicenter Trial of Intensive Early Intervention vs Standard Treatment for Patients With a First Episode of Psychotic Illness: The OPUS Trial. *Arch Gen Psychiatry*, 65(7):762-771.
- Birchwood, M., Todd, P., & Jackson, C. (1998). Early intervention in psychosis. The critical period hypothesis. *Br J Psychiatry*, 172 (suppl. 33), 53-59.
- Burns, T,. Fioritti, A., Holloway, F., Malm, U., & Rössler, W. (2001). Case Management and Assertive Community Treatment in Europe. *Psychiatr Serv*, 52: 631-636.
- Center for Psychiatric Rehabilitation (2009), http://www.bu.edu/cpr/resources/factsheets/
- Clarke, M., Whitty, P., Browne, S., McTigue, O., Kinsella, A., Waddington, J.L. Larkin, C., & O'Callaghan, E. (2006). Suicidality in first episode psychosis. *Schizphr Res*, 86(1-3):221-5.
- Collins, M.E., Bybee, D., & Mowbray, C.T. (1998). Effectiveness of supported education for individuals with psychiatric disabilities: Results from an Experimental study. *Commun Mental Health J*, 34, 595-613.
- Craig, T.K.J., Garety, P., Power, P., Rahaman, N., Colbert, S., Fornells-Ambrojo, M., & Dunn, G. (2004). The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *BMJ*, 329: 1067.
- Cuijpers, P. (1999). The effects of family interventions on relatives' burden: a meta-analysis. *J Mental Health*, 8:275-285.
- Department of Human Services (2000) Primary Mental Health and Early Intervention Services.Victoria: DoHS.
- Department of Health (2000) The NHS Plan: A Plan for Investment. A Plan for Reform. London: DoH.
- Dixon, L. (2000). Assertive Community Treatment: Twenty-Five Years of Gold. *Psychiatr Serv*, 51, 759-765.
- Drake, R.E., & Deegan, P.E. (2008). Are Assertive Community Treatment and Recovery, Compatible? Commentary on 'ACT and Recovery: Integrating Evidence-based Practice and Recovery Orientation on Assertive Community Treatment Teams'. *Commun Mental Health J*, 44:75–77.
- Drake, R., Essock, S., Shaner, A., et al. (2001). Implementing dual diagnosis services for clients with severe mental illness. *Psychiatr Serv, 2*, 469-476.
- Drake, R., Goldman, H., Leff, H., Lehman, A., Dixon, L., Mueser, K., Torrey, W., & William, C. (2001). Implementing Evidence-Based Practices in Routine Mental Health Service Settings. *Psychiatr Serv*, 52, 179-182.

- Dutch Guideline for Schizophrenia [Multidisciplinaire richtlijn Schizofrenie; Richtlijn voor de diagnostiek, zorgorganisatie en behandeling van volwassen cliënten met schizofrenie (2005). *Trimbos-instituut,* www.ggzrichtlijnen.nl.
- Edwards, J., Harris, M.J., & Bapat, S. (2005). Developing services for first-episode psychosis and the critical period. *Br J Psychiatry*, 187 (suppl. 48), 91-97.
- Farkas, M., Gagne, C., Anthony, W.A., & Chamberlin, J. (2005). Implementing Recovery Oriented Evidence Based Programs: Identifying the Critical Dimensions. *Commun Mental Health J*, 41 (2), 141-158.
- Garety, P., Craig, T., Dunn, G., et al. (2006). Specialised care for early psychosis: symptoms, social functioning and patient satisfaction: randomised controlled trial., *Br J Psychiatry,* 188, 37-45.
- Goffman, E. (1961). *Asylums. Essays on the social situation of mental patients and other inmates,* Harmondsworth: Penguin, 1968. First published New York: Doubleday Anchor, 1961.
- Haddock, G., & Lewis, S. (2005). Psychological treatment of early psychosis. *Schizophrenia Bull*, 31, 697-704.
- Hazel, N.A., Mcdonell, M.G., Short, R.A., Berry, C.M., Voss, W.D., Rodgers, M.I., & Dyck, D.G. (2004). Impact of multiple-family groups for outpatients with schizophrenia on caregivers' distress and resources. *Psychiatr Serv,* 55:35-41.
- Häffner, H., Maurer, K., Löffler, W., et al. (1994). The epidemiology of early schizophrenia: Influence of age and gender on onset and early course. *Br J Psychiatry*, 162:658-664 (suppl):29-38.
- Hoenig, J. (1983). The concept of Schizophrenia. Kraepelin-Bleuler-Schneider. *Br J Psychiatry*; 142: 547-556.
- International Early Psychosis Association writing group (2005). International clinical practice guidelines for Early Psychosis. *Br J Psychiatry,* 187 (suppl. 48), 120-124.
- NVOLVE, (2004), http://www.invo.org.uk/Conference2004.asp.
- Jeppesen, P., Petersen, L., Thorup, A., Abel, M.B., Øhlenschlæger, J., Christensen, T., Krarup, G., Hemmingsen, R., Jorgenson, P., & Nordentoft, M. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden: OPUS trial. *Br J Psychiatry,* 187, (Suppl. 48), 85-90.
- Johannessen, J.O., Friis, S., Joa, I., Haahr, U., Larsen, T.K., Melle, I., Opjordsmoen, S., Rund, B.R., Simonsen, E., Vaglum, P., & McGlashan, T. (2007). First-episode psychosis patients recruited into treatment via early detection teams versus ordinary pathways: course, outcome and health service use during first 2 years. *Early Intervention in Psychiatry;* 1: 40–48.
- Jorgensen, P., Nordentoft, M., Abel, M.B., et al. (2000). Early detection and assertive community treatment of young psychotics: the Opus Study Rationale and design of the trial. *Soc Psychiatry Psychiatr Epidemiol*, 35, 283-287.

- Kuipers, E., Holloway, F., Rabe-Hesketh, S., Tennakoon, L. (2004). An RCT of early intervention in psychosis: Croydon Outreach and Assertive Support Team (COAST). *Soc Psychiatry Psychiatr Epidemiol*, 39, 358–363.
- Kroon, H., & van Erp, N. (2002). Een sterke ketting, met zwakke schakels – onderzoek naar begeleid leren voor mensen met psychische beperkingen. Utrecht: *Trimbos-instituut*.
- Liberman modules (2008), http://lczorg.rinogroep.nl/?pageID=90.
- Marshall, M., & Lockwood, A. (1998). Assertive Community Treatment for those with severe mental disorders, *Cochrane Library*, vol. 5, no. 2.
- Meeuwissen, J., Weeghel, Van, J. (2003). Modulenboek bij het stepped-care programma voor depressie. Utrecht: Trimbos-instituut, Programma Diagnostiek & Behandeling.
- McDonel, E.C., Bond, G.R., Salyers, M., Fekete, D., Chen, A., McGrew, J.H., & Miller, L., (1997). Implementing Assertive Community Treatment Programs in Rural Settings. *Admin Policy Mental Health, 25, (21), 153-173.*
- McFarlane, W.R. (1997). FACT: Integrating Family Psychoeducation and Assertive Community Treatment. *Admin Policy Mental Health Serv Res, 25,* (2), 191-198.
- McGorry, P.D., Edwards, J., & Mihalopoulos, C., et al. (1996). EPPIC: An evolving system of early detection and optimal management. *Schizophrenia Bull,* 22, 305-326.
- McGorry, P.D., & Pelosi, A.J. (2004). Value of early intervention in psychosis. *British Journal of Psychiatry*, 185, 172.
- McGorry, P.D., Purcell, R., Hickie, I.B., Jorm, A.F. (2007), Editorial Investing in youth mental health is a best buy. *MJA,* 187 (7 Suppl): 5-7.
- McHugo, G.J., Drake, R.E., Teague, G.B., & Xie, H. (1999). Fidelity to Assertive Community Treatment and Client Outcomes in the New Hampshire Dual Disorders Study. *Psychiatr Serv, 50*: 818-824.
- Mowbray, C.T., Bybee, D., & Collins, M.E. (2001). Follow up client satisfaction in a supported education program. *Psychiatr Rehabil J*, 24, 237-247.
- Mueser, K., Bond, G., Drake, R., & Resnick, S. (1998). Models of community care for severe mental illness: a review of research on case management. *Schizophrenia Bull*, 24, 37-74.
- Mueser, K.T., Salyers, M.P., & Mueser, P.R. (2001). A prospective analysis of work in schizophrenia. *Schizophrenia Bull*, 27, 281-296.
- National Early Psychosis Project Clinical Guidelines Working Party (1998). *Australian Clinical Guidelines for Early Psychosis.* Melbourne: National Early Psychosis Project, University of Melbourne.
- Nordentoft, M., Jeppesen, P., Abel, M., Kassow, P., Petersen, L., et al. (2002) OPUS study: suicidal behaviour, suicidal ideation and hopelessness among patients with first-episode psychosis. One-year follow-up of a randomised controlled trial. *Br J Psychiatry,* 43: 98-106.

- Nordentoft, M., Jeppesen, P., & Petersen, L. (2003). OPUS project: a randomised controlled trial of integrated psychiatric treatment in first-episode psychosis. *Schizophrenia Res,* 60, 297.
- Pelosi, A.J., & Birchwood, M. (2003). Is early intervention for psychosis a waste of valuable resources? *Br J Psychiatry,* 182 (3):196-198.
- Petersen, L., Jeppesen, P., Thorup, A., Abel, M., Øhlenschlæger, J., Christensen, T., et al. (2005). A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *BMJ,* 331: 602-605.
- Petersen, L., Jeppesen, P., Thorup, A., Ohlenschlaeger, J., Krarup, G., Ostergard, T., Jorgensen, P., & Nordentoft, M. (2007). Substance abuse and first-episode schizophrenia-spectrum disorders. The Danish OPUS trial. *Early Interven Psychiatry,* 1 (1), 88–96.
- Power, P., Iacoponi, E., Reynolds, N., Fisher, H., Garety, P., McGuire, P., Russell, M., & Craig, T. (1998). The LEO CAT study: A cluster randomised trial of GP education and access to an early detection team in first episode psychosis. *Br J Psychiatry, 191* (suppl. 51), 133-139.
- Power, P., McGuire, P., Iacoponi, E., Garety, P., Morris, E., Valmaggia, L., Grafton, D., & Craig, T. (2007). Lambeth Early Onset (LEO) and Outreach & Support in South London (OASIS) service. *Early Interven Psychiatry,* 1 (1), 97-103.
- Roick, C., Heider, D., Bebbington, P.E., Angermeyer, M.C., Azorin, J.-M., Brugha, T,H., Kilian, R.. Johnson, S., Toumi, M., & Kornfeld, Å. (2007) Burden on caregivers of people with schizophrenia: comparison between Germany and Britain. *Br J Psychiatry,* 190, 333-338.
- Rosen, A., Mueser, K.T., & Teesson, M. (2007). Assertive community treatment-Issues from scientific and clinical literature with implications for practice. *J Rehabil Res Dev,* 44(6): 813-826.
- Salyers, M.P., & Tsemberis, S. (2007). ACT and Recovery: Integrating Evidence-Based Practice and Recovery Orientation on Assertive Community Treatment Teams. *Commun Mental Health J,* 4, 6.
- Spaniol, L.S., Wewiorski, N.J., Gagne, C., & Anthony, W.A. (2002). The process of recovery from schizophrenia. *Int J Psychiatr,* 14(4), 327-336.
- Stein, L.L., & Santos, A.B. (1998). Assertive Community Treatment of persons with Severe Mental Illness. New York, Norton.
- Stein, L.I., Test, M.A., & Marx, A.J. (1975). Alternative to the hospital: a controlled study. *Am J Psychiatr,* 132:517–522.
- Teague, G., Bond, G., & Drake, R. (1998). Program fidelity in assertive community treatment: development and use of a measure. *Am J Orthopsychiatry,* 68, 216-232.
- Test, M., & Stein, L. (2001). A Critique of the Effectiveness of Assertive Community Treatment. Psychiatr Serv, 52, 1396-1397.
- Thornicroft, G. (2000). Testing and Retesting Assertive Community Treatment. *Psychiatr Serv,* 51, 703.

- UK700 Group: Burns, T., Creed, F., Fahy, T., et al. (1999) Intensive versus standard case management for severe psychotic illness: a randomized trial. *Lancet*, 353:2185–2189.
- Waldron, H.B., Turner, C.W., & Clin, J. (2008). Evidence-based psychosocial treatments for adolescent substance abuse. *Child Adolesc Psychol*, 37(1):238-261.
- Weisbrod, B.A., Test, M.A., & Stein, L.L. (1980). Alternative to mental hospital treatment: II. Economic benefit-cost analysis. *Arch Gen Psychiatr*, 37:400–405.
- Yung, A.R., McGorry, P.D. (1996). The prodromal phase of first- episode psychosis: Past and current conceptualizations. *Schizophrenia Bull*, 22, 353-370.
- Yung, A., Organ, B., & Harris, M. (2003). Management of early psychosis in a generic adult mental health service. *Austral NZ J Psychiatry*, 37, 429-436.

CHAPTER 2

STUDY DESIGN, TARGET GROUP, OFFERED SEVICES, OUTCOME MEASUREMENTS, AND STUDY DROP-OUTS

This chapter presents an overview of the study design, the experimental and control groups, the two types of treatment conditions, the outcome measures and drop-out rates.

Study design

The design used is quasi-experimental, also called the Non-Equivalent Groups Design. It is one of the most frequently used designs in social research. Although its structure is similar to a pretest-posttest randomized experiment, it lacks the key feature of a randomized design.

The control group was located in Tilburg where we collected data from medical files, as well as from professionals who completed questionnaires (Clinical Global Impression, CGI and the Global Assessment of Functioning, GAF scale) and were interviewed by telephone. For the experimental group (Eindhoven) we collected data from professionals (questionnaires and interviews), from carers (questionnaires, and group feedback meetings) and from patients (questionnaires, medical files, and group feedback meetings).

In the present study, random assignment to each condition was not possible because of the experimental treatment provided, and because some patients were already receiving Care as Usual (CAU). Assertive Community Treatment (ACT) is supposed to be provided within the community; this critical feature of ACT could not be realised if patients were randomly assigned to one of the two conditions because the travelling times would make ACT too cost-inefficient. Moreover CAU in Tilburg is partly integrated in heterogeneous target groups (i.e. teams North and South). Separating the patients and arranging them into a homogeneous group would have caused major organizational problems; this made it impossible to design a proper randomised clinical trial.

Inclusion criteria at baseline

In both groups the following criteria were used to include patients in the study:

- client suffers from a first-episode psychosis;
- client recently (in the last year) had first positive symptoms;
- clients are diagnosed with psychotic disorders, including schizophrenia and all its sub-types;
- client adequately understands/speaks the Dutch language.

Clients suffering from organic psychiatric disorders and clients with a mental retardation comorbidity (IQ <80) were excluded.

THE TARGET GROUP

The members of the target group are mostly in the age group 18-35 years and recently had their first-episode psychosis. The target group comprised 149 patients: 105 in the experimental group and 44 in the control group. The average age of the total population was 26 years and 76% was younger than 35 years. The age of the patient was determined on the date that ACT and CAU commenced, i.e. shortly after remission of the client's first psychosis. No significant difference was found between the two groups for gender and age, but there were differences in the DSM-IV classifications. The control group consisted of more patients diagnosed with schizophrenia or subtypes (38%) compared to the experimental group (25%). In the other prominent group of patients, diagnosed with Psychotic Disorder NOS, there was a reverse distribution, 32% in the control group and 42% in the experimental group.
At baseline the control group scored higher on the job/school characteristic. In the control group 45% had a job or went to school versus 34% in the experimental group. At baseline, more patients in the experimental group lived on their own (51%) than patients in the control group (38.6%). More patients in the control group lived with their parents (38.6%) than members of the experimental group (31%). About 10% of the patients in the experimental group were looking for an independent living facility versus 2.3% in the control group. Of the experimental group 8% was admitted or lived in a house for sheltered living compared with 20.5% in the control group. At baseline, the control group showed a similar level of "good/moderate social adjusted" (92%) compared with the experimental group (93.3%).
The numbers of patients diagnosed with Schizophrenia and with Psychotic Disorders NOS was almost equal in both groups, except that they have a different, reverse distribution. This can be explained by a delay in transfer from crisis intervention services to the treatment setting or to a different use of the DSM-IV in the control condition.
In this study to determine the Duration of Untreated Psychosis (DUP) we took the moment patients got involved in specialized mental health treatment (e.g. psychiatric ward of an general hospital or crisis ward of a psychiatric hospital). The moment patients got their first psycho-pharmaceutical treatment was mostly not traceable and also retrospectively difficult to assess whether the provided medication was adequately in the then situation. For that reason the here assessed DUP's are just indicative and must be interpreted as defined by Craig, et al. (2002). Furthermore in this study we couldn't determine DUP score of control group patients. In the experimental condition the DUP shortened over 4 years from 3½ months in 2004, at the start of the ACT treatment, till 2 months in 2008 (table 1).
We compared the available bed-capacity for clinical crisis intervention of both regions, included all crisis beds of general hospital wards. In the region of Tilburg (control group) for each 100.000 inhabitants 19 crisis intervention beds are available. The occupation degree over the last 4 years was on average 96%. In the region of Eindhoven for each 100.000 inhabitants 23

crisis intervention beds are available. The occupation degree over the last 4 years in Eindhoven was on average 93%. There were no changes in the numbers of beds in both regions during the last 4 years.

Table 1. Characteristics of the target groups: ACT (experimental) group and the CAU (control) group at baseline

	ACT (n=105)	CAU (n=44)
Gender		
Male	82 (78.1%)	31 (70.5%)
Female	23 (21.9%)	13 (29.5%)
Age (years)		
Mean	26.3 (SD 8.1)	25.3 (SD 8.5)
Range	16-52	17-54
DSM-IV		
295.xx[1]	26 (24.8%)	17 (37.7%)
298.9[2]	44 (41.9%)	14 (31.8%)
DUP	Median = 3 months	-
Job/school		
Yes	8 (8%)	9 (21%)
with IPS or support	27 (26%)	11 (24%)
No (occasionally)	39 (37%)	14 (31%)
not ready	30 (29%)	10 (24%)
Housing		
yes, own	53 (51%)	17 (38.6%)
yes, with parents	32 (31%)	17 (38.6%)
looking for own	10 (10%)	1 (2.3%)
no, admitted/sheltered	9 (8%)	9 (20.5%)
Social adjusted		
yes	64 (61.9%)	31 (70%)
moderate	33 (31.4%)	9 (21%)
no	7 (6.7%)	4 (9%)

[1] Schizophrenia and all subtypes

[2] Psychotic Disorder, not otherwise specified

Experimental and control group

Experimental group

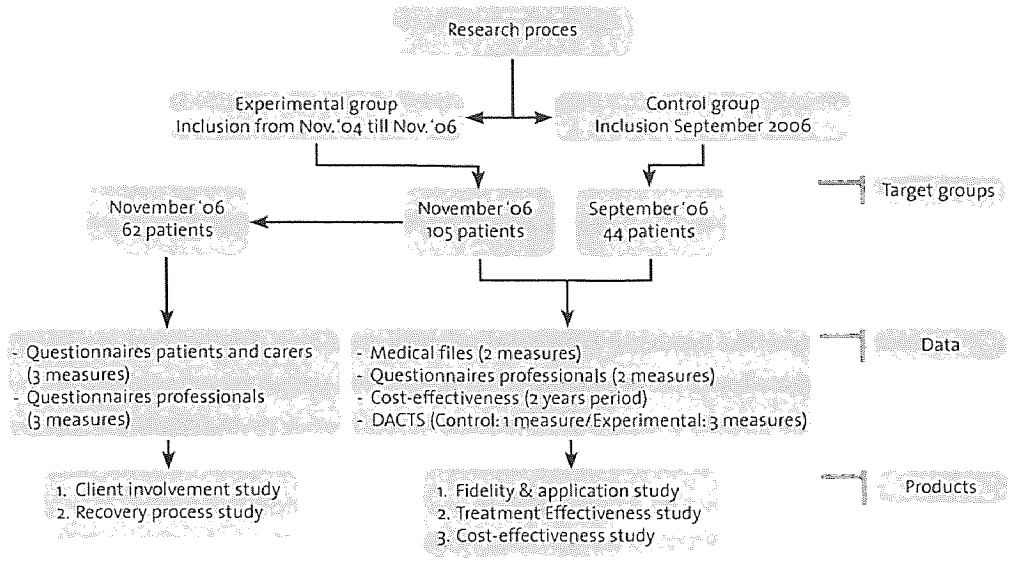
The majority of patients in the ACT group were aged 18 to 35 years and recently had their first-episode psychosis. In most cases the patients were recruited from a crisis intervention service within six weeks after the appearance of their first positive symptoms. This means that the DUP is relatively short (median score at baseline was 3 months).

Recruitment for the ACT group started in November 2004 by including those patients who were already in treatment at that moment (n=29); these 29 patients had their first-episode psychosis in the year (November 2003-2004) prior to the inclusion date. The ACT group increased over time based on regular referrals from acute services in the region. By November 2005 ACT had included 70 patients and by November 2006 (when the last client was included) the group consisted of 105 patients. Data from this experimental group were used to compare the outcome effects between this group and the control group (Chapter 5), and for the cost-effectiveness study (Chapter 7).

Of the 105 included patients, 62 completed questionnaires. The data obtained from the questionnaires were used to gain more insight into the recovery process and the contribution of ACT to that process. Of these 62 patients, 51 completed all 3 measurement instruments (7 patients completed 2 measurements, and 4 patients completed only 1 measurement). Data collected from this ACT group were used for the studies in Chapter 4 (Client involvement in mental health research) and in Chapter 6 (ACT, early psychosis and recovery) (Figure 1).

The scores on the Clinical Global Impression (CGI) and the Global Assessment of Functioning (GAF) revealed a selection bias between the two ACT sub-groups. On the whole, the 105 members in the ACT group were more severely ill than the 62 patients who signed informed consent, i.e. the latter had better CGI and GAF scores, and had fewer relapses.

Figure 1. Flow chart of the study protocol



Control group

We began by determining the locations where all patients suffering from a psychosis were treated, and learned that they were divided between two geographically-based treatment teams for adults, and one treatment team for youth. The two adult teams treat patients aged 18 years and older with different kinds of diagnoses; the youth team treats a similar heterogeneous group, but up to age 23 years only.

Via the local case managers, all related professionals were asked to provide the names of clients who meet the study inclusion criteria. The characteristics of the selected patients were then carefully checked against the inclusion criteria. We then selected the proposed clients from the electronic medical file system and performed an additional search (in the age range 17-35 years) on all DSM-IV diagnosis types related to psychosis. At the same time we checked the psychiatric wards of the two local general hospitals to establish whether they treat young clients suffering from psychosis. The psychiatrists of these wards assured us that they only provide crisis intervention services and transfer all patients to the CAU control group within (on average) 3 months.

All clients in the control group were already receiving treatment at the moment of inclusion in the present study (October 2006); no additional clients were included after October 2006. Some data were acquired retrospectively for the period that these patients had already received treatment since their first positive symptoms, and for a few patients the two-year data set was completed in July 2008.

Services offered to experimental and control group

Services provided to the experimental group (ACT)

Disciplines, services and specialties

The ACT team consist of a psychiatrist (0.7 FTE), a physician (0.4 FTE), psychologists (1.5 FTE), vocational trainers (1.5 FTE), social psychiatric nurses (4.3 FTE), a housing specialist (0.9 FTE), and a peer group specialist (0.9 FTE). The team members provide several services (see below). There is no one-to-one relationship between services and disciplines. Besides the shared services (e.g. case management) the individual disciplines deliver their own specialty-related services. For example, the psychologists provide diagnostic activities (neuropsychological tests) and supportive therapy for parents and partners, the social nurses provide psychoeducation and act as experienced dual-diagnosis specialists, the physicians prescribe medication, and the housing specialist offers support regarding accommodation and various financial matters.

Case management

The ACT team is responsible for a group of patients; there is no individual caseload. If a patient prefers to have contact with one professional, this is allowed to some extent. However, the team has to be informed about treatment policy and continuity has to be assured. In this way all disciplines fulfil a kind a case management. The only discipline that provides case management in a specific sense is the social psychiatric nursing service. These nurses focus on social functioning and role fulfilment, control for (side-)effects of medicines and medication compliance, intervene in family and carer systems, apply crisis intervention techniques, and provide psychoeducation. Important issues include: hope(lessness), empowerment, motivation, grieving, suicidal behaviour, family burden, risks and safety of the home situation, and family members (Teague, et al., 1998).

Cognitive Behavioural Therapy (for those with delusions and hallucinations)

Cognitive Behavioural Therapy (CBT) identifies and monitors thoughts, assumptions, beliefs and behaviours that are related to and accompanied by debilitating negative emotions, and identifies those which are dysfunctional, inaccurate, or simply unhelpful. The intervention aims to replace or transcend the negative/inadequate thoughts or behaviours with more realistic and useful ones (Addington, et al., 2006; Haddock, et al., 2005). Frequently treated subjects include inferiority, negative feelings/self-image, and low self-esteem. A frequently applied variant of CBT for psychotic patients is the 'unravelling of thoughts and ideas' (Gaag, 2005).

Psychoeducation in family and client groups

The purpose of the psychoeducation sessions is to increase patients' and carers' knowledge and understanding of illness and treatment. It is assumed that increased knowledge enables people with psychosis to cope more effectively with their illness. Psychoeducation is a strongly recommended item within the service supply. It is provided separately to carers and patients to allow maximum attention to be paid to specific demands and issues. The training addresses several issues related to psychosis and how to deal with it. A wide range of advice, solutions and experiences are shared among the participants. Important themes are: what is psychosis, what is its aetiology, the prognosis and consequences, how to deal with positive and negative symptoms, medication (side-effects, compliance), is there hope, and how to prevent family burden (what is the impact on parents and siblings)? (Jeppesen, 2005; Dixon, 2000; Dutch Guideline for Schizophrenia, 2005).

Integrated Dual-Diagnosis treatment

The ACT provides elements of an Integrated Dual-Diagnosis treatment model. This means an integrated treatment for autonomous but interacting disorders (e.g. a psychiatric disorder and substance abuse). The dual-diagnosis treatment requires specially trained staff to deal with the two autonomous processes and their interaction. The team members provide Motivational interviews, psychoeducation (e.g. regarded risks, effects and interaction with anti psychotic medication), and individual social skill trainings (e.g. regarded to offensive behaviour of dealers or avoiding seductive circumstances) (Drake, 1998; Minkoff, 1998; Prochaska, & DiClemente, 1992).

Vocational training and school support

Vocational training and school support aims to assist patients in choosing, gaining and maintaining a job, education or day activities, starting from an evidence-based practice (Individual Placement and Support and Supported Education techniques) (Bond, 1998; Collins, 1998). Starting from an individual goal the vocational trainer actively intervenes in all phases of the process to attain the defined goal. The trainer collaborates with each patient and involves parties such as employers, local social services, employment agencies and, in case of school support teachers, the student counselor and parents.
When a client has functional disabilities or handicaps the vocational trainer arranges relevant support to compensate for this. The challenge is to find suitable work or schooling, despite the patient's handicap, disability or special needs.

Housing and financial support

The ACT professional focuses on providing patients with a place to live of their own choice. He operates within social networks and negotiates with housing companies, parents and others to find the best solution for the housing needs of the patient. This item has some priority because

homelessness often leads to hospitalization. The housing specialist deals with all types of related issues, e.g. financial, hygiene, nutritional, getting furniture, et cetera.

Individual and peer group support

The peer group worker is a professional, fully responsible and informed member of the team. He operates from his own experiences combined with techniques on how to apply the experiences in an optimal balance between maximum involvement whilst still maintaining a professional distance. The peer group worker provides a low-threshold access and focuses on thoughts, anxieties and uncertainties related to the patient's disorders. Important interventions are sharing experiences, listening to and recognition of the patient's stories to put the patient's mind at rest. Whenever possible, the peer worker gives advice based on his own experience. In group sessions he uses experiences, ideas and advice from group members and initiates social activities, e.g. visiting a museum or a sports facility (Simpson, 2003).

Pharmacotherapy

Pharmacotherapy is a key element in ACT treatment. When patients are transferred to ACT generally they are already on medication for psychosis and/or depression. First of all, the psychiatrist always connects with the patient (and their carers) and always starts from the present medication policy and professional guidelines. Except for emergency situations, pharmacotherapy is primarily based on the aim to achieve consensus. This requires motivational techniques, adequate information about effects and side-effects, and strategies to enhance compliance. The patient-professional dialogue is considered an important way to complete a successful pharmacological policy and to steer a middle course between the benefits of medication and the (possible) undesired side-effects experienced by the patient (IEPA writing group, 2005; Dutch Guideline for Schizophrenia, 2005).

Services provided to the control group (CAU)

In the present study, 'care as usual' is defined as all services provided to the control group. This group consists of three subgroups: Team Youth (n=20), Team North (n=3) and Team South (n=21). The patients in the three subgroups have comparable characteristics; distribution within the groups is based on age, and on historical and geographical parameters. Because there were many similarities between teams North and South the same basic description was used for both.

CAU: services and ideology

In the control condition, care takes place by means of 'stepped care'. This means that (in the first instance) the most effective, least burdensome, cheapest and shortest way of treatment possible (given the nature and gravity of the situation) will be offered. When this intervention

proves to be insufficiently effective or inadequate, a more intensive intervention is selected (Meeuwissen, & Weeghel, 2003).

In case of stepped care, most clients are referred by a general practitioner or via a crisis intervention service to a psychiatrist and/or a social psychiatric nurse. Together these professionals draw up a treatment plan; after that, most patients receive low-intensive outreach care and day (or part-time) treatment. Should problems occur, the level of care can be upgraded on the specific request of the patient, the community/carers or professional staff. This means that some patients receive temporary additional outpatient services, such as CBT or family treatment. When those treatment arrangements prove to be insufficient, day treatment or inpatient (crisis intervention) care is available. Patients may also receive additional help from the local authority (e.g. in finding a suitable job or accommodation), or parallel help for their substance abuse.

The service model "Youth"
The standard service that every client receives is case management (coordination, plus more/less psychosocial treatment) by a psychiatric nurse, and pharmacological therapy. For all clients the case manager connects with the social network, in most cases the family members. Medication is considered an important part of the total treatment. The case manager monitors medication compliance and motivates the clients when they fail to take their medication.
In addition, about two-thirds of the group receive (more or less, as required) psychiatric rehabilitation-oriented services and living support; this does not involve systematic evidence-based interventions (such as supported employment or supported education). Some members of this group may be referred to a ward (i.e. part of their own mental health organisation) for occupational training.
About one-third of the group has to be considered as 'intensive treatment' patients. They occasionally get CBT and specific referral to dual-diagnosis services, in or outside their own organisation. After the first year when stabilisation is achieved, patients are often referred to day and/or part-time treatment.

The service model "Teams North and South"
The case managers of teams North and South have a central position and are responsible for the treatment process of the assigned patients. The case manager is a coordinator, the contact person for family and other colleagues (e.g. general practitioner or local government authorities), completes (together with the client) the treatment plan, and arranges additional services such as CBT, rehabilitation services (Liberman modules), parallel or sequential dual-diagnosis treatment, day and part-time treatment, and sheltered accommodation. The case manager can also act as a 'buddy' for the patient and carers, as a counselor/therapist, or as an advisor in financial or business matters of the client.

In summary, CAU can be characterised as a traditional stepped-care treatment, centred around a case manager (social psychiatric nurse) that is responsible for the recovery process of a large number of patients. Also here, medication is considered to be an important part of the total treatment. The case manager monitors medication compliance and motivates clients when they fail to take their medication. The case manager has a pivotal role in CAU, managing the entire process and consulting with other disciplines when necessary.

A comparison between ACT and CAU reveals similarities as well as large differences. Firstly, the focus on the homogeneous target group 'clients in their early phase of psychosis' makes ACT a specialised facility with specific specialists for this target group. Their team approach and vision is prominent: i.e. assertive outreach and (from the very beginning) focused on clients gaining/regaining their social roles (work, friends, family and school) and responsibilities in society. Only in case there is no other option, a client is admitted to a clinic for a short period of time.

Other major differences between ACT and CAU are the organization of the treatment model and the presence of specialised interventions and knowledge (e.g. vocational training and school support, dual-diagnosis treatment, peer support, and housing support in ACT). The main differences between the two conditions concern (beside the variety of the services) organizational model characteristics, and the intensity of the applied (outreaching) services.

Treatment fidelity in both conditions

The fidelity rate of ACT is the extent to which it meets the features of the original model, expressed in the measure on the Dartmouth Assertive Community Treatment Scale (DACTS), a fidelity scale. The DACTS consists of 28 items, each rated on a 5-point behaviourally-anchored scale: a score of 4.2 or more indicates 'full implementation', 3.0 to 4.2 indicates 'moderate implementation', and 1.0 to 3.0 indicates a 'low degree of implementation' (Salyers, et al., 2003). The importance of measuring fidelity emerged after a UK study (Burns, et al., 2002) which showed smaller effect differences between ACT and CAU compared with American studies. This result was mainly attributed to a higher fidelity level among the CAU groups. For this reason, to interpret the findings of the present study correctly, we measured the fidelity level of both the CAU and ACT conditions.

Fidelity in ACT

The fidelity of ACT was measured three times (Table 2): in September 2004, in November 2005 and again in March 2007, using the DACTS (Teague, et al., 1998). DACTS measurements were carried out by an independent researcher and by the first author. Data were collected jointly and later scored independently. This resulted in a high inter-rater reliability; of the 28 items only 2 items showed a difference of maximally 1 point on a 5-point scale.

Table 2: DACTS scores of ACT fidelity as assessed in 2004, 2005 and 2007

	September 2004	November 2005	March 2007
Team structure	4.2	4.6	4.4
Organization	3.6	4.8	4.4
Services	2.7	3.5	3.7
Total DACTS score [1,2]	3.5	4.3	4.2

[1] Score range is from 1–5; a higher score indicates a higher fidelity

[2] Total score is the mean of 3 sub-scores (team structure, organization and services)

Fidelity in CAU

In contrast to the usual procedure (see Chapter 3), for the organisational items we interviewed the local manager, and for the program content items we interviewed the professional who was most familiar with the target group. In all cases the DACTS Score Sheet was used as a guideline. During the interviews it became clear that the information provided by the manager and by the professional showed considerable overlap; this was used to check whether the provided data were reliable. A third data source, providing specific insight in CAU, were the patient records that were examined twice for all patients in the control group (n=44).

The fidelity scores show that CAU does not consist of many of the ACT characteristics. An average score from 1.0 to 3.0 indicates a 'low degree of implementation' (Salyers, et al., 2003).

The overall score for CAU is calculated based on the number of clients in each of the three subgroups. However, because the teams Youth and South were similar in size but Team North was much smaller, the averaged scores were weighted 1:1:1/6 for these sub-groups. Table 3 presents the individual team scores and the overall scores.

Table 3. DACTS scores of the CAU fidelity assessment in the control group.

	Youth team (n=21)	Team South (n=19)	Team North (n=3)[1]	Total score (n=43)
Team structure	2.1	2.8	2.0	2.4
Organization	2.7	3.3	2.3	2.9
Services	1.8	1.7	1.4	1.7
Total DACTS score[1,2]	2.2	2.6	1.9	2.4

[1] Score range is from 1–5; a higher score indicates a higher fidelity
[2] Total score is the mean of 3 sub-scores (team structure, organization and services)

Outcome measurements

A broad range of data was assessed from the medical/registration files, questionnaires and interviews, which can be divided into 4 main areas: quality of life (QoL), psychosocial, psychopathology, and an additional group of measurements. We deliberately chose to collect data from different perspectives in order to acquire an overview of the experiences of all parties involved that was as complete as possible: i.e. a consumer's perspective from the patients and carers (QoL area), a clinical perspective from the professionals (psychosocial and psychopathology area), and a research/organizational perspective related to fidelity and cost-effectiveness.

In the following chapters, specific parts of the collected data were used and applied in order to address each of the research questions.

Quality of life area

Two measurement instruments were used to determine the effects experienced by patients: the brief version of the WHO Quality of Life scale (WHO QOL-BREF) (Vries de, and Heck van, 1996), and the Empowerment Scale (Rogers, et al., 1997).

The questionnaires were completed by patients with support from either the client interviewers or the staff interviewers (Verhaegh, 2008). After the first measurement we ad random checked 20 patients to see whether support for the second and third measurements would be of any additional value. Most patients (n=15) indicated that they were able to complete the additional questionnaires themselves. Five patients (mostly non-Dutch) indicated that they needed continued support, which was provided.

The WHO QOL-BREF comprises 26 items which measure the following domains: physical health, psychological health, social relationships, and environment. The Dutch version was used in all cases, except for one patient who preferred the English version. The psychometric features of the WHO QOL-BREF are reported to be good (Trompenaars, et al., 2005).

Empowerment is described as an individual process that requires a number of qualities to be able to control one's life and take a more prominent, worthy and influential position in the community. The Centre for Psychiatric Rehabilitation has reported 15 typical elements, including: decision-making power, access to information and resources, a range of options from which to make choices, assertiveness, making a difference, thinking critically, feeling part of a group, coming 'out of the closet', permanent growth and change, and overcoming stigma.

The Empowerment scale (Rogers, et al., 1997) comprises 6 subscales: Self Esteem/Self-Efficacy, Power/Powerlessness, Community Activism and Autonomy, Optimism and Control over the Future, Righteous Anger, and Overall Empowerment. The Empowerment scale has shown adequate validity in a population of outpatient mental health clients (Wowra, 1998; Scott, et al., 1999).

Psychosocial area

For this area we collected data from medical files concerning the number of hospital admissions, the number of (tentative) suicide attempts, social adjustment, housing, substance abuse, school/work situation, and compliance with treatment and medication. These data were used to compare the outcome of the two treatment conditions. The measures we used are frequently used as outcome measures, and as indicators of effectiveness in ACT studies (Nordentoft, et al., 2008; Kuipers, et al., 2004; Dixon, et al., 2000; McGrew, et al., 1995; Spaniol, et al., 2002).

For this area we also collected data using the Demand-oriented Care list that examines the client's (psychosocial) demands and the extent to which the offered services meet these needs. This list has also shown sufficient validity (Weert-van Oene de, et al., 2006).

For family burden we used the Involvement Evaluation Questionnaire (Wijngaarden van, et al., 1997) which consists of 7 subscales: living circumstances and relationship to the patient, intensity of support, quality of the relationship with the patient, level of concern about the patient, financial consequences, own health condition, and impact on the patient's children.

In addition, data from the Health of Nation Outcome Scale (HoNOS) (subscale social functioning) and client files were used to describe results in this area, such as: work/school, relationships, living situation, and (leisure) activities.

Psychopathology area

The clinical effects of ACT were examined using 4 instruments:

- the Positive and Negative Syndrome Scale (PANSS) which measures positive/negative symptoms and general psychopathology on 3 subscales (Kay, 1987).
- the Health of Nation Outcome Scale (HoNOS) which considers different aspects of mental and social health, each scored on a scale from 0-4. The scale consists of 4 subscales (behaviour, impairments, social, and symptoms) and has been shown to have sufficient validity and reliability (Mulder, 2004; Wing, 1996).
- the Clinical Global Impression (CGI) which is designed to assess the global severity of illness and change in the clinical condition over time. The scale consists of 3 global subscales: severity of illness, global improvement, and efficacy index. The Dutch version used in the present study consists of the first two subscales only (Nolen, 2008).
- the Global Assessment of Functioning is a single-item rating scale for clinicians to rate the overall psychosocial functioning of patients; it has 10 anchor points and continuous scores ranging from 1-100 (Endicott, et al., 1976).

Additional group

For this we collected data from the registration files for the cost-effectiveness study. We also performed DACTS measurements for the research question addressed in Chapter 3.

Study drop-outs

In this part of the study we were able to include all the patients and there were no drop-outs by the end of the two-year study period. In case a patient moved from one area to another and thus changed their mental health organisation generally the files were available for several months before they were closed. For a few patients the files were not available for a follow-up measurement. In that case we asked the most involved professional to trace the missing data and this was achieved in all cases.

For measurement of the recovery process in the ACT group, data were obtained from questionnaires completed by team members: i.e. (client) researchers, patients and carers. For this target group the inclusion procedure was as follows. Professionals who were close to the patients invited them to participate in an outcome/effect study. If they agreed, the patient was included and signed informed consent. From the original 105 ACT patients, 62 were included in this part of the study. Of those 62, data were available for 58 patients (4 completed only 1 measurement which ruled out comparisons over time). From those 58 patients we have data from 2 measurement points, and from 51 of those patients we have data from all 3 measurement points (i.e. at baseline, after 1 year, and after 2 years). The missing

measurements were caused by crises, a stay in prison, or temporary loss of motivation. In 4 patients the research contact continued after the treatment had finished. In these cases we were able to collect data for the full two-year study period.

In this sub-group, 5 patients moved away: 1 emigrated to Finland, 1 took a temporary job in England, and 3 moved to other cities in the Netherlands. However, all were motivated to complete the questionnaires, despite the travelling distance. Some parts of their questionnaires were completed autonomously and the remainder was completed at an ACT location; these appointments were often combined with family visits or vacations.

References

- Addington, J., & Haarmans, M. (2006). Cognitive-Behavioral Therapy for Individuals Recovering from a First Episode of Psychosis. *J Contemp Psychother,* 36,(1), 43-49.
- Bond, G.R. (1998). Principles of the Individual Placement and Support model: Empirical support. *Psychiatric Rehabil J,* 22, 1.
- Burns, T., White, I., Byford, S., Fiander, M., Creed, F., & Fahy, T. (2002). Exposure to case management: relationships to patient characteristics and outcome: Report from the UK700 trial. *Br J Psychiatry,* 181, 236-241.
- Collins, M.E., Bybee, D., & Mowbray, C.T. (1998). Effectiveness of supported education for individuals with psychiatric disabilities: Results from an Experimental study. *Comm Mental Health J,* 34, 595-613.
- Craig, T.K.J., Garety, P., Power, P., Rahaman, N., Colbert, S., Fornells-Ambrojo, M., & Dunn, G. (2004). The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *BMJ,* 329: 1067.
- Dixon, L. (2000). Assertive Community Treatment: Twenty-Five Years of Gold. *Psychiatric Serv,* 51, 759-765.
- Drake, R.E., McHugo, G.M., Clark, R.E., Teague, G.B., Ackerson, T., Xie, H., & Miles, K.M. (1998). A clinical trial of assertive community treatment for patients with co-occurring severe mental illness and substance use disorder. *Am J Orthopsychiatry,* 68:201-215,
- Dutch Guideline for Schizophrenia (Multidisciplinaire richtlijn Schizofrenie) (2005). *Onder auspiciën van de Landelijke Stuurgroep Multidisciplinaire Richtlijnontwikkeling in de GGZ.*
- Endicott, J., Spitzer, R.L., Fleiss, J.L., Cohen, J. (1976). The Global Assessment Scale: A procedure for measuring overall severity of psychiatric disturbance. *Arch Gen Psychiatr,* 33, 766-771.
- Gaag, van der, M., Valmaggia, L.R., Meer, van, C.R., & Slooff, C.J. (2005). *Gedachten uitpluizen: Handboek Theorie. Cognitieve gedragstherapie bij achterdocht en stemmen.* Oegstgeest: Stichting Cognitie en Psychose, www.gedachtenuitpluizen.nl.
- Haddock, G., & Lewis, S. (2005). Psychological treatment of early psychosis. *Schizophrenia Bull,* 31, 697-704.
- International Early Psychosis Association writing group (2005). International clinical practice guidelines for Early Psychosis. *Br J Psychiatry,* 187 (suppl. 48), 120-124.
- Jeppesen, P., Petersen, L., Thorup, A., Abel, M.B., Øhlenschlæger, J., Christensen, T., Krarup, G., Hemmingsen, R., Jorgenson, P., & Nordentoft, M. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden: OPUS trial. *Br J Psychiatry,* 187 (suppl. 48), 85-90.
- Kay, S.R., Fiszbein, A. & Opler, L.A. (1987). The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bull,* 13, (2), 261-276.

- Kuipers, E., Holloway, F., Rabe-Hesketh, S., & Tennakoon, L. (2004). An RCT of early intervention in psychosis: Croydon Outreach and Assertive Support Team (COAST). *Soc Psychiatry Psychiatr Epidemiol*, 39, 358–363.
- Meeuwissen, J., Weeghel, Van, J. (2003). Modulenboek bij het stepped-care programma voor depressie. Utrecht: Trimbos-instituut, Programma Diagnostiek & Behandeling.
- Minkoff, K. (1997). Integration of Addiction and Psychiatric Treatment. In Miller NS (ed) The Principles and Practice of Addictions in Psychiatry. Philadelphia: WB Saunders Company.
- McGrew, J.H., Bond, G.R., Dietzen, L., McKasson, M., & Miller, L.D., (1995). A multisite study of client outcomes in assertive community treatment. *Psychiatr Serv*, 46,696-701.
- Mulder, C.L., Staring, A.B.P., Loos, J., Buwalda, V.J.A., Kuijpers, D., Sytema, S., & Wierdsma, A.I. (2004). De Health of the Nation Outcome Scales (HoNOS) als instrument voor 'routine outcome assessment', *Tijdschrift voor Psychiatrie*, 46, 5, 273-284.
- Nolen, W., (2008). Clinical Global Impression Scale, www.tijdschriftvoorpsychiatrie.nl/meet-instrumenten/download.php?id=29.
- Nordentoft, M., Thorup, A., Petersen, L., Øhlenschlæger, J., Christensen, T., Krarup, G., et al. (2008). Does a detection team shorten duration of untreated psychosis? *Early Interven Psychiatr*, 2, 22–26.
- Prochaska. J.O., DiClemente, C.C. (1992). Stages of change in the modification of problem behaviours, *Prog Behav Modif*, 28:183-218. Review.
- Rogers, E.S., Chamberlin, J., Ellison, M., & Crean, T. (1997). A consumer-constructed scale to measure empowerment. *Psychiatr Serv*, 48(8), 1042-1047.
- Salyers, M., Bond, G., Teague, G., Cox, J., Smith, M., Hicks, M., et al. (2003). Is it ACT yet? Real-world examples of evaluating the degree of implementation for assertive community treatment. *Journal of Behavioral Health Services & Research*, 30, 304-20.
- Scott, A., Wowra, B.A., McCarter, R. (1999). Validation of the Empowerment Scale With an Outpatient Mental Health Population. *Psychiatr Serv*, 50:959-961.
- Simpson, E.L., Barkham, M., Gilbody, S. & House, A. (2003). Involving service users as service providers for adult statutory mental health services. The Cochrane Database of Systematic Reviews, Issue 4.
- Spaniol, L.S., Wewiorski, N.J., Gagne, C., & Anthony, W.A. (2002). The process of recovery from schizophrenia. *Int J Psychiatr*, 14(4),327-336.
- Teague, G.B., Bond, G.R., & Drake, R.E. (1998). Program fidelity in assertive community treatment: development and use of a measure. *Am J Orthopsychiatr*, 68, 216-232.
- Trompenaars, F.J., Masthof, E.D.M., Heck van, G.L., Hodiamont, P.P.G., & Vries, de, J. (2005). Content validity, construct validity, and reliability of the WHO QOL-BREF in a population of Dutch adult psychiatric outpatients. *Qual Life Res*, 14(1), 151-160.

- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. (2008). Cliënten als ervaringsdeskundig interviewer in wetenschappelijk onderzoek, De betekenis voor de kwaliteit van de verzamelde data en het herstelproces van de interviewers. *Tijdschrift voor Rehabilitatie.* [Client involvement in mental health research: effects on quality of data and on the r ecovery process of the interviewers. *Dutch Journal of Rehabilitation].*
- Vries, J. de, & Heck, G.L. van (1997). The World Health Organization quality of life assessment instrument WHO QOL-100: Validation study with the Dutch version. *Eur J Psychol Assess*, 13(3), 164-178.
- Weert-van Oene de, G.H., Buwalda, V.J.A., Havenaar, J.M., Swildens, W., Keijzerswaard van, A., & Schrijvers, A.J.P., (2006). Demand-oriented care: the development and validation of a measuring instrument. *Social Psychiatry Psychiatr Epidemio*, W41, 215-220.
- Wijngaarden van, B & Schene, A.H. (1997). The Involvement Evaluation Questionnaire (European Version). *Amsterdam: Department of Psychiatry*, University of Amsterdam.
- Wing, J., Lelliott, P., Chaplin, R.H. (1999) Reliability and validity of HoNOS (multiple letters). *Psychiatric Bull*, 23 (6):375.
- Wowra, S.A., McCarter R. (1999) Validation of the Empowerment Scale with an outpatient mental health population. *Psychiatr Serv*, 50,959-961.

CHAPTER 3.

MODEL FIDELITY OF ASSERTIVE COMMUNITY TREATMENT FOR CLIENTS WITH FIRST-EPISODE PSYCHOSIS: INDICATIONS FOR TARGET GROUP-SPECIFIC APPLICATIONS

Abstract

Assertive Community Treatment is described as a team treatment model designed to provide assertive, outreaching, comprehensive, community-based, rehabilitation-oriented and supportive psychiatric services for people with severe mental illness (Drake, et al., 2001; Teague, Bond, & Drake, 1998). This study explores variations in the way the original components of ACT are implemented for the target group of clients with a first-episode psychosis, and establishes whether these variations lead the treatment model to a higher, more valuable, outcome level. The study also describes how to achieve this optimally effective application of target group-specific treatment services.

Introduction

Assertive Community Treatment (ACT) is a well-known evidence-based practice (EBP) that is frequently applied because of its positive impact on, in particular, the target group of severely mentally ill persons (Marshall, & Lockwood, 1998; Drake, et al., 2001; Dixon, 2000; Teague, Bond, & Drake, 1998; Mueser, Bond, Drake, & Resnick, 1998). Nevertheless, some criticize ACT for being too costly or too intensive, and because not all studies show the same effect sizes. The latter can probably be attributed to poor model fidelity in the experimental condition and to the improved quality of the examined 'care as usual' (Billings, et al., 2003; Killaspy, et al., 2006). Regarding the high costs of ACT, intensive treatment with a caseload of 1:10 applied in times of economic recession has provoked criticism (Fenwick, & Byford, 2005; Test, & Stein, 2001; Byford, et al., 2000). However, this does not prove that ACT is not cost-effective on the long term. Finally, some argue that resources should not be spent too quickly and to the full extent; a stepped-care approach is suggested by these critics. However, when it becomes obvious that low-intensity care is not (sufficiently) effective, it is justified to implement more intensive alternatives. This way of assigning care avoids taking responsibility away from the client and ensures e.g. hospitalization in the client's own surroundings (Davison, 2000).

Why ACT for clients with a first-episode psychosis?

First of all ACT is increasingly and successfully applied for clients with a first-episode psychosis (Petersen, et al., 2005; Nordentoft, Jeppesen, & Petersen, 2003). Both from literature and own clinical experience in the last 3 years we know what percentage of the total group of clients will have a relapse but we don't know exactly who in specific will relapse (Wiersma, Nienhuis, Slooff, & Giel, 1998; Vlaminck, 2003; Addington, Addington, & Patten, 2007). For this reason the ACT-staff chose to apply ACT for the total group of clients. Events in the first 3-5 years after the appearance of the first positive symptoms of psychosis (the critical period) determine the future course of the recovery process and functioning of the client (Spencer, Birchwood, & McGovern, 2001; McGlashan, 1999; Scully, Coakley, Kinsella, & Waddington, 1997).

A positive correlation has been shown between improved outcome of treatment and a shorter Duration of Untreated Psychosis (DUP) (Marshall, et al., 2005; McGlashan, 2005; McGorry, Nordentoft, & Simonsen, 2005; McGorry, & Pelosi, 2004; Norman, Lewis, & Marshall, 2005; Perkins, Gu, Boteva, & Lieberman, 2005). An assertive approach of an ACT-team towards referred clients could be a meaningful feature in shortening the DUP also (Nordentoft, et al., 2008). Furthermore research demonstrates the cost-effectiveness of ACT. Due to decreasing usage of clinical services the total costs were 20% lower than 'care as usual' (McGorry, Killackey, & Yung, 2007; Jeppesen, et al., 2005).

Importance of model fidelity

Both the founders and those who adapt ACT emphasize the importance of fidelity in implementing the ACT; a positive outcome is attributed to full implementation of the original model (Burns, et al., 2002; Drake, et al., 2001; McGrew, & Bond, 1995a; Priebe, et al., 2004; Test, & Stein, 2001; Weaver, Tyrer, Ritchie, & Renton, 2003). When applying ACT to a new target group it has to be precluded that the outcome (or absence thereof) can be attributed to poor fidelity (Kuipers, Holloway, Rabe-Hesketh, & Tennakoon, 2004). A pilot study has shown that ACT in the Netherlands has many shortcomings with regard to model fidelity (Dijk van, Roosenschoon, Kroon, & Mulder, 2004).

Effect studies have shown the importance of determining model fidelity in both the experimental and the control condition. Studies in the UK noted that care as usual contains many aspects of ACT (Burns, et al., 2002). This was partly the explanation for the smaller difference between the effects of the two conditions compared with the results of earlier studies from the USA.

Target group-specific applications

Mowbray, Holter, Teague, & Bybee (2003) distinguish between intentional adaptation of EBP and adapting a model unintentionally. Unintentional adaptation often occurs due to poor knowledge of the model one wants to apply, and an insufficient check on actual practice and implementation of the model. In both cases this results in reverting to old habits and losing the EBP.

The consequences and disadvantages of unintentionally applied adaptations are associated with the importance of a high fidelity adaptation of EBP (such as described above). Intentional adaptations enable to justify the choices made, to compare the adapted model to the original, and to establish the level of (increased) effectiveness (Mowbray, et al., 2003).

A high fidelity implementation of EBP means a doctrinal operation (Barkham, & Mellor-Clark, 2003). In practice, however, circumstances may occur that provide reasons to adapt or modify EBP. Adapting the original model purposively is possible and sometimes even necessary, e.g. in case of a new insurance system or divergent geographical circumstances. Another reason for purposively tailoring an EBP is to apply that practice in a totally new or slightly different target group (Bond, Evans, Salyers, Williams, & Kim, 2000; Mowbray, et al., 2003; Henskens, Garretsen, Mulder, Bongers, & Kroon, 2005; McGrew, Bond, Dietzen, McKasson, & Miller, 1995b).

Variation is also possible on the condition that it happens judiciously and to a limited extent. EBP's have several critical components that determine the essence of the model. Changing

these components implies loss of fidelity and consequently decreased effectiveness. Making changes to the non-critical components has been shown to improve the effectiveness of the model (Bond, Drake, Mueser, & Latimer, 2001).

The following features of ACT are considered to be critical (Table 1): a multidisciplinary team, integrated care, a team approach, low caseload, within the community, psychopharmacologic treatment, care is aimed to everyday needs, quick crisis intervention, assertive attitude, individual approach, and the offer is preferably not time-limited (Bond, et al., 2001).

The present study explores the possibility of achieving a better treatment outcome by intentionally applying a 'full implemented' ACT-model to the demands of a new group of clients with first-episode psychosis. Hereby we followed the above mentioned insights in intentionally changing EBP's and describe how it is achieved.

Table 1: Critical and non-critical components of ACT (Bond, et al., 2001)

Critical components	Non-critical components
• multidisciplinary team	• intake rate
• integrated care	• staff continuity
• team approach	• practicing leader
• low caseload	• program meeting
• act in community	• discharge planning responsibility
• psychopharmacologic treatment	• no dropout
• care is aimed to everyday needs	• work with support system
• quick crisis intervention	• group substance abuse treatment
• assertive attitude	• dual disorder model
• individual	• hospital admission responsibility
• the service is aimed not-time-limited	• team complement
	• explicit admission criteria
	• staff capacity

Three research items are addressed: 1) the fidelity rate of ACT in this research to mark the starting point, 2) the degree to which the present services are demand oriented, and 3) the effects of implementing the suggested improvements whilst preserving the critical components.

Methods

In July 2004 a mental healthcare organization in the southern part of the Netherlands (Mental Healthcare Eindhoven) started to treat a group of clients according to the principles of ACT. The target group consists of all customers with a first-episode psychosis (excluding substance-induced psychotic disorders), generally in the age group 18 to 35 years. The catchment area comprises 450,000 inhabitants of whom 210,000 live in a city.

The fidelity of ACT was measured three times (in September 2004, in November 2005 and again in March 2007) using the Dartmouth Assertive Community Treatment Scale (DACTS) (Teague, Bond, & Drake, 1998). DACTS measurements were carried out by two trained researchers (one independent external researcher and the first author); data were collected jointly and later scored independently. This resulted in a high inter-rater reliability; of the 28 items only 2 items showed a difference of maximally 1 point on a 5- point scale.

The DACTS consists of 28 items, each rated on a 5-point behaviourally-anchored scale with a score of 4.2 or more indicating 'full implementation', 3.0 to 4.2 indicating 'moderate implementation', and 1.0 to 3.0 indicating a 'low degree of implementation' (Salyers, et al., 2003).

After one year the ACT team received practice-based feedback concerning the degree to which, according to the customers and caregivers, the received services correspond to their needs/demands (Barkham, & Mellor-Clark, 2003). All clients (n=70) received a questionnaire consisting of two open questions: What do you like about ACT? and Which of the offered services do you not like? A covering letter requested the caregiver to answer the questions together with the client. In case the client was unable to answer the questions, the caregivers were asked to complete the questionnaire instead.

A team member and a program leader analyzed the qualitative data and, compiled an overview of the positive/negative responses, and highlighted the 4 topics that appeared to need improvement. These topics/points of interest were presented to four key figures (wellinformed colleagues who were not a team member) who recognized the impact of these topics during the last year and judged them to be essential.

The modified data were presented and discussed at a meeting with clients and their caregivers (n=75) and staff members (n=10). The participants were divided into eight subgroups, with equal numbers of men/women and clients/caregivers. The subgroup discussions were supervised by independent chairpersons who were well informed about ACT; none was a team member. Uniformity of the discussions was promoted by the use of standard protocols. The subgroups held discussions for 1.5 hours concerning the points of interest.

In November 2005 the above-described method was repeated. Clients and caregivers were again asked for their feedback on the services received. The data were again discussed, as previously, during a (family) group meeting.

Results

The first measurement (September 2004) of model fidelity produced an average DACTS implementation score of 3.5 (Table 2)

Table 2: DACTS scores[1] of fidelity assessment in 2004, 2005 and 2007

	September 2004	November 2005	March 2007
Team structure	4.2	4.6	4.4
Organization	3.6	4.8	4.4
Services	2.7	3.5	3.7
Total score[2]	3.5	4.3	4.2

[1] DACTS score range is from 1–5; a higher score indicates a higher fidelity
[2]The total score is the mean of 3 sub scores (team structure, organization and services)

The strikingly low score on the subscale Services (2.7) was caused by the fast inclusion of clients at the start of the project, the low frequency of contact per client, and the absence of a double-diagnosis expert and of a peer group worker. The score on the subscale Team structure was negatively affected when a staff member left at the start of the project, and a substance abuse expert was lacking. The subscale Organization was negatively influenced by a high inclusion rate and poor collaboration with the acute care ward in the first months. The second measurement (November 2005) produced a total score of 4.3 indicating 'complete implementation'. The improved score is a result of successfully dealing with the points of interest mentioned above, and completing the team with the missing experts.

The third DACTS-score in March 2007 showed a stable fidelity level (total score was 4.2), which indicates that after the target group-specific applications the ACT-model is still 'full implemented'.

Of the 70 questionnaires distributed, 54 were returned (response 77%). In 20% of the cases the client filled in the questionnaire alone mainly because of the lack of (or a poor) social network. The majority of the questionnaires (60%) were filled in by the clients together with the caregiver(s). The caregiver(s) answered alone in 20% of the cases, mostly because their client was in a crisis or was not motivated to respond.

In their answers, 36 respondents (66.7%) mentioned only positive characteristics of the services, 16 (29.6%) reported both positive and negative aspects, and 2 respondents (3.7%) gave only negative feedback (Tables 3 and 4).

Table 3: Experienced positive features of service model mentioned by respondents (N=54)

	%	n
Demand oriented, good care	63	34
Easy to contact because of team approach	50	27
Support to parents	37	20
The intensity of the services	33	18
Care in community	9	6
Offered psycho-education	6	4
Vocational and school support	6	4
Capable and enthusiastic team	6	4
Peer group support	6	4
Well-informed team	6	4

The positive responses were generally in agreement with the critical components of ACT. The respondents mentioned the multidisciplinary team approach, tailored care, integrated care, the low caseload, community in care, and well-organized crisis intervention. The assertive attitude was considered positive, but some criticisms were also reported (Table 4). Not specifically mentioned by the respondents were: pharmacological therapy, care aimed not to be time-limited, and focusing on everyday needs.

Four points of interest emerged from the family group meeting:

1) Communication between the ACT team and the parties involved (including clients/ caregivers); a need for the following improvements were indicated:
   - Clients and caregivers emphasized the need for cooperation with support systems (DACTS item 24). They requested better information about ACT (e.g. a folder, Internet site or newsletter), the use of e-mail communication, and more attention paid to inform primary healthcare. The team must be more explicit about their expectations

concerning the role of parents in the treatment process. The respondents stress the importance of family psychological training. This point also concerns closer inter-pretation of DACTS item 12, i.e. clear criteria of inclusion. Caregivers complain, mostly afterwards, about the long delay before referral to ACT.

- Caregivers ask team members to act more assertively towards primary healthcare professionals and other partners in the network such as housing companies, financial institutions, or payment agencies. Agencies wait too long before they indicate that something is threatening to go wrong.
- A good level of communication is associated with the small-scale of ACT (DACTS item 22, intensity of services). The small scale of operation should be maintained to guarantee optimal communication.

2) Service accessibility and availability of the team. The clients report shortages regarding contact, especially (telephonic availability) after office hours. This applies to both regular contacts with a team member and crisis intervention (DACTS item 15, responsibility for crisis services). Respondents indicate that ACT services during office hours with an additional crisis intervention ward are often inadequate.

3) Match between care demand and services offered. There is a need for more variations in therapy, e.g. peer group meetings and family/caregiver groups. Caregivers indicate that they also need psychological training. Caregivers also want more knowledge and support concerning legislation, financial and vocational matters. There is also a need for occupational activities and leisure support. More attention should be paid to pharmacotherapy, especially to the side effects of medication (problems with concentration, extra pyramidal symptoms, fatigue, and impotence).

Table 4: Experienced negative features of service model mentioned by respondents (N=54)

	%	n
Contactability after office hours	24	13
Communication should be better	13	7
Insufficient contact with issuing authority	13	7
Services are not assertive enough	13	7
Insufficient vocational support	6	4
Too little support on financial issues	6	4
Not enough peer group contacts	6	4
Search for accommodation takes too long	6	6
Not enough contact with parents/caregivers	6	4
Concerns about new crises	6	4
Insufficient services	6	4
Appointment system not satisfactory	6	4

The results are related to DACTS items 24 (cooperation with support system), 7 and 8 (specific attention and expertise of nurses/psychiatrists) and 10 (the capacity of vocational trainers).

4) Attitude of the professionals: this was judged to be too non-committal. Caregivers should have a more assertive attitude, as described in the original model. Professionals must act more directly and more proactively.

After 1 year 88 questionnaires were distributed; after one reminder 67 were returned (response 76%). This time, in 27% of the cases the client filled in the questionnaire independently; in 22% of the cases the questionnaires were filled in by the clients and caregiver(s) together, and in 51% the caregiver(s) answered the questionnaires alone.
In their answers, 27 respondents (40%) mentioned only positive characteristics of the services, 39 (58%) reported both positive and negative features, and 1 respondent gave only negative feedback.

The evening meeting was attended by about 100 persons; 80 were clients/caregivers and 20 were professionals. The positive responses were similar to those reported in the first year. The level of availability in the weekends and evenings had been extended and is now considered a positive point. The professionals showed a more assertive attitude, and the increased attention to clients' finances has also become a positive point.

New critical points emerging are: availability during the daytime, the busy agenda of professionals when an appointment is needed on the short term, and appointments are changed too often.

Discussion

This study investigated whether target group-specific applications on bases of a 'full implemented' ACT-model improve the outcome, and described how this can best be achieved. We examined whether the original ACT model in this study was fully implemented. Subsequently, data were collected that indicated specific applications to be made on the original model when applied to clients with a first-episode psychosis. Then, positive and negative items were discussed against the background of the (non-)critical components of the model, and suggestions for improvements were made.

After one year of ACT the model has been fully implemented and clients/caregivers indicate that the provided services adequately meet the critical components of the original ACT model and answer the care demands of both clients and caregivers. Whether quantitative data will produce the same positive outcome is not yet established; our research data are still being analysed.

Based on the results of the questionnaires and the family group meetings, the model has been applied according to the demands of the target group and caregivers on a number of points. Regarding communication: the target group now makes more use of latest media such as SMS and e-mail, as do the professionals. The team will inform regional parties and colleagues more effectively about the ACT.

Regarding accessibility and availability: accessibility has been successfully extended to (parts of) the evening and the weekends; the extra hours have been synchronised with school and working hours. There does not seem to be a need for a separate crisis intervention service because clients have more frequent contact with caregivers. The emergency telephone can also be used for less urgent matters. All these applications are positively appreciated.

Clients and caregivers would like better harmonisation between services and care demands; i.e. they ask for services to focus more specifically on the target group and caregivers, and give more attention to support with regard to financial problems, vocational and pharmacological issues. The attention paid to financial matters has improved according to both clients and caregivers.

Finally, caregivers and clients asked for a more assertive attitude of professionals when clients do not comply with the treatment plan. This is a characteristic of ACT, but had not been strongly implemented. It seems, however, that the present target group needs less assertiveness than the group with severe mental illness. For example, most of our young

people seemed to comply easily and there was almost no dropout. Nevertheless, the team did act more assertively and pro-actively, especially in situations that threaten to go wrong. It became clear that especially the caregivers appreciate this positively.

The new points of attention (accessibility, availability and planning of appointments) have resulted in increased capacity in the secretarial office.

Neither clients nor caregivers mentioned the characteristic 'not-time-limited care'; this is because the team had not yet formulated a discharge policy. Later on, because of the large number of admissions and limited treatment capacity, the team placed the item "not-time-limited" on the agenda. The team decided to transfer care to a case manager 3 years after the appearance of the first symptoms of psychosis. However, the results of the OPUS study (Bertelsen, et al., 2008) have shown that when ACT stops after 2 years, after an additional 3-year period the client reverts to the same level of functioning as clients who received care as usual only, i.e. the health advantages achieved with ACT disappeared completely. This seems to show that during the critical period ACT is indicated for 5 years rather than 3 years. The results presented here relate to the target group of clients with a first-episode psychosis. Based on the incidence rates it has been calculated that 8 of the 10 persons with a first-episode psychosis belong to the target group of the ACT team treatment. In the present study, 77% of this group have been represented and we have no reason to assume that this proportion is not representative for the total population. These results, however, may be influenced by the local circumstances, i.e. the service model has been applied for only 2 years, and the team members are ambitious and enthusiastic about this novel treatment.

Conclusions and recommendations

According to the moderate scores on the DACTS, implementation of the current Dutch mental healthcare ACT services shows a poor level of fidelity (Dijk, van, et al., 2004). It seems that implementations of the model occur coincidentally rather than intentionally. Local and practical circumstances tend to determine the content and structure of the model. This article describes an intentional target group-specific application of an EBP based on feedback from the clients and caregivers. The goal was to achieve a treatment-model that responds to the specific care demands of the present target group and afterwards to examine whether it still meets the (critical) characteristics/components of ACT. The suggested points of interest of clients and caregivers match the characteristics of the original ACT model. The service can be improved by better compliance with the original features or a more demand driven variant of the existing characteristics. None of the suggestions made by the clients and caregivers were incompatible with or missing from the DACTS items. Therefore, our results indicate that all

(critical) components of ACT are suitable for this target group. One year after the target group specific applications were realized, the model is still 'full implemented' according to the DACTS-score. For our target group of clients the desired applications were: communication with target group members and network partners, and more emphasis on aspects of daily living (e.g. accommodation, finances, work, schooling) and the consequences of choices to be made (taking into account schooling, working hours and (side) effects of medication. Involving caregivers in the healthcare process (e.g. family groups, psycho-education) was of great importance for the clients and caregivers and is considered a possible critical feature for this target group. Another critical item was related to greater availability of vocational rehabilitation expertise. A final new feature of future ACT-teams could be an assertive approach towards referral parties. In the ACT region the median of the DUP is less than two months likely due to the presence of this feature. In this study a systematically evaluation of both the (fidelity of an) EBP and to what
extent it meets the needs of families and clients has proven to be successful and, more in general, seems to be crucial to achieve an optimal application of EBP's for new target groups. An annual e-mail questionnaire in combination with a meeting of clients and caregivers appears to be an effective feedback method to improve the services and to evaluate their effectiveness.

References

- Addington, D., Addington, J., & Patten, S. (2007). Relapse rates in an early psychosis treatment service. *Acta Psychiatrica Scandinavica*, 115: 126-131.
- Barkham, M., & Mellor-Clark, J. (2003). Bridging evidence-based practice and practice-based evidence: developing a rigorous and relevant knowledge for the psychological therapies. *Clinical Psychology & Psychotherapy*, 10 (6) 319-327.
- Bertelsen, M., Jeppesen, P., Petersen, L., Thorup, A., Øhlenschlæger, J., le Quach, P., et al. (2008). Five-Year Follow-up of a Randomized Multicenter Trial of Intensive Early Intervention vs Standard Treatment for Patients With a First Episode of Psychotic Illness: The OPUS Trial. *Archives of General Psychiatry*, 65(7):762-771.
- Billings, J., Johnson, S., Bebbington, P., Greaves, A., Priebe, S., Muijen, M., et al.(2003). Assertive outreach teams in London: staff experiences and perceptions: Pan-London Assertive Outreach Study, Part 2. *British Journal of Psychiatry*, 183, 139-147.
- Bond, G., Drake, R., Mueser, K., & Latimer, E. (2001). Assertive Community Treatment for people with severe mental illness. Critical ingredients and impact on patients. *Disease Management & Health Outcomes*, 9, 3, 142-157.
- Bond, G., Evans, L., Salyers, M., Williams, J., & Kim, H. (2000). Measurement of Fidelity in Psychiatric Rehabilitation. *Mental Health Services Research*, 2, 2, 75-87.
- Burns,T., White, I., Byford, S., Fiander, M., Creed, F., & Fahy, T. (2002). Exposure to case management: relationships to patient characteristics and outcome: Report from the UK700 trial. *British Journal of Psychiatry*, 181, 236-241.
- Byford, S., Fiander, M., Torgerson, D., Barber, J., Thompson, G., Burns,T., et al. (2000). Cost-effectiveness of intensive v. standard case management for severe psychotic illness: UK700 case management trial. *British Journal of Psychiatry*, 176, 537-543.
- Davison, G. (2000). Stepped Care: Doing More With Less? *Journal of Consulting and Clinical Psychology*, 68(4) 580-585.
- Dijk, van, B., Roosenschoon, B., Kroon, H., & Mulder, C. (2004). Modelgetrouwheid van Assertive Community Treatment in Nederland [Model fidelity of Assertive Community Treatment in Holland]. *Maandblad Geestelijke volksgezondheid*, 59, 931-943.
- Dixon, L. (2000). Assertive Community Treatment: Twenty-Five Years of Gold. *Psychiatric Services*, 51, 759-765.
- Drake, R., Goldman, H., Leff, H., Lehman, A., Dixon, L., Mueser, K., et al. (2001). Implementing Evidence-Based Practices in Routine Mental Health Service Settings. *Psychiatric Services*, 52, 179-182.
- Fenwick, E.P., & Byford, S.M. (Red). (2005). A guide to cost-effectiveness acceptability curves. *British Journal of Psychiatry*, 187, 106-108.

- Henskens, R., Garretsen, H., Mulder, C.L., Bongers, I., & Kroon, H. (2005). Fidelity of an Outreach Treatment Program for Chronic Crack Abusers in the Netherlands to the ACT Model. *Psychiatric Services, 56*, 1451-1454.
- Holloway, F., & Carson, J. (2001). Review Article Case Management: an Update. *International Journal of Social Psychiatry*, 47,21-31.
- Jeppesen, P., Petersen, L., Thorup, A., Abel, M.B., Øhlenschlæger, J., Christensen, T., et al. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden: OPUS trial. *British Journal of Psychiatry, 187 SUPPLEMENT* 48, s85-s90.
- Killaspy, H., Bebbington, P., Blizard, R., Johnson, S., Nolan, F., Pilling, S., et al. 2006. The REACT study: randomised evaluation of assertive community treatment in north London. *BMJ*, 332, 815-820.
- Kuipers, E., Holloway, F., Rabe-Hesketh, S., & Tennakoon, L. (2004). An RCT of early intervention in psychosis: Croydon Outreach and Assertive Support Team (COAST). *Social Psychiatry and Psychiatric Epidemiology*, 39 (5) 358-363.
- Lewin Group (2000). *Assertive Community Treatment, Literature Review Prepared For: Health Care and Financing Administration (HCFA) And Substance Abuse and Mental Health Services Administration (SAMHSA).*
- Marshall, M., & Lockwood, A. (1998). Assertive Community Treatment for those with severe mental disorders, *Cochrane Library*, vol. 5, no. 2.
- Marshall, M., Lewis, S., Lockwood, A., Drake, R., Jones, P., & Croudace, T. (2005). Association between duration of untreated psychosis and outcome in cohorts of first-episode patients: a systematic review, *Archive of General Psychiatry*, vol. 62, no. 9, pp. 975-983.
- McGlashan, T. (1999). Duration of untreated psychosis in first-episode schizophrenia: marker or determinant of course? *Biological Psychiatry*, 46, 899-907.
- McGlashan, T. (2005). Early detection and intervention in psychosis: an ethical paradigm shift. *British Journal of Psychiatry*, 187, 113-115.
- McGorry, P.,Killackey, E., & Yung, A. (2007). Early intervention in psychotic disorders: detection and treatment of the first episode and the critical early stages. *Medical Journal of Australia*, 187 (7 Suppl): S8-S10
- McGorry, P., Nordentoft, M., & Simonsen, E. (2005). Introduction to 'Early psychosis: a bridge to the future'. *British Journal of Psychiatry*, 187, 1-3.
- McGorry, P.D., & Pelosi, A.J. (2004). Value of early intervention in psychosis. *British Journal of Psychiatry*, 185, 172.
- McGrew J., & Bond, G. (1995a). Critical ingredients of assertive community treatment: judgments of the experts. *Journal of Mental Health Administration*, 23, 113-125.

- McGrew, J., Bond, G., Dietzen, L., McKasson, M., & Miller, L. (1995b). A multisite study of client outcomes in assertive community treatment. *Psychiatric Services*, 46, 696-701.
- Mowbray, C., Holter, M., Teague, G., & Bybee, D. (2003). Fidelity Criteria: Development, Measurement, and Validation. *American Journal of Evaluation*, 24, 315-340.
- Mueser, K., Bond, G., Drake, R., & Resnick, S. (1998). Models of community care for severe mental illness: a review of research on case management. *Schizophrenia Bulletin*, vol. 24, no. 1, 37-74.
- Nordentoft, M.,Thorup, A., Petersen, L., Øhlenschlæger, J., Christensen,T., Krarup, G., et al. (2008). Does a detection team shorten duration of untreated psychosis? *Early Intervention in Psychiatry*, 2: 22–26.
- Nordentoft, M., Jeppesen, P., & Petersen, L. (2003). OPUS project: a randomised controlled trial of integrated psychiatric treatment in first-episode psychosis. *Schizophrenia Research*, 60, 297.
- Norman, R., Lewis, S., & Marshall, M. (2005). Duration of untreated psychosis and its relationship to clinical outcome. *British Journal of Psychiatry*, 187, s19-s23.
- Perkins, D., Gu, H., Boteva, K., & Lieberman, J. (2005). Relationship Between Duration of Untreated Psychosis and Outcome in First-Episode Schizophrenia: A Critical Review and Meta-Analysis. [Miscellaneous Article]. *American Journal of Psychiatry*, 162, 1785-1804.
- Petersen, L., Jeppesen, P., Thorup, A., Abel, M., Øhlenschlæger, J., Christensen, T., et al. (2005). A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *British Medical Journal*, 331: 602-5.
- Priebe, S., Fakhoury, W., White, I., Watts, J., Bebbington, P., Billings, J., et al. (2004). Characteristics of teams, staff and patients: associations with outcomes of patients in assertive outreach. *British Journal of Psychiatry*, 185, 306-311.
- Salyers, M., Bond, G., Teague, G., Cox, J., Smith, M., Hicks, M., et al. (2003). Is it ACT yet? Real-world examples of evaluating the degree of implementation for assertive community treatment. *Journal of Behavioral Health Services & Research*, 30, 304-20.
- Scully, P., Coakley, G., Kinsella, A., & Waddington, J. (1997). Executive (frontal) dysfunction and negative symptoms in schizophrenia: apparent gender differences in 'static' v. 'progressive' profiles. *British Journal of Psychiatry*, 171, 154-158.
- Spencer, E., Birchwood, M., & McGovern, D. (2001). Management of first-episode psychosis. *Advances in Psychiatric Treatment*, 7, 133-140.
- Teague, G., Bond, G., & Drake, R. (1998). Program fidelity in assertive community treatment: development and use of a measure. *American Journal of Orthopsychiatry*, 68, 216-232.
- Test, M., & Stein, L. (2001). A Critique of the Effectiveness of Assertive Community Treatment. Psychiatric Services, 52, 1396-1397. B Thornicroft, G. (2000). Testing and Retesting Assertive Community Treatment. *Psychiatric Services*, 51, 703.

- Veldhuizen, van, R. (2005). Assertive Community Treatment. Maandblad Geestelijke volksgezondheid, 60, 449-452.
- Vlaminck, P. (2003). De moderne aanpak van psychose [Modern treatment of psychosis]. *Uitgeverij: Eburon*, Delft.
- Weaver, T., Tyrer, P., Ritchie, J., & Renton, A. (2003). Assessing the value of assertive outreach: Qualitative study of process and outcome generation in the UK700 trial. *British Journal of Psychiatry*, 183, 437-445.
- Wiersma, D., Nienhuis, F.J., Slooff, C.J., & Giel, R. (1998). Natural course of schizophrenic disorders: a 15-year follow-up of a Dutch incidence cohort. *Schizophrenia Bulletin*, 24(1):75-85.

CHAPTER 4

CLIENT INVOLVEMENT IN MENTAL HEALTH RESEARCH: EFFECT ON QUALITY OF DATA AND COURSE OF THE INTERVIEWS

Abstract

Objective

Client involvement[1] in research is controversial. This study describes the involvement of clients in mental health research. Two questions are addressed: 1) what influence do client interviewers have on the quality of the collected data and 2) on the course of the interviews.

Methods

Within an ongoing study on the effects of Assertive Community Treatment (ACT) for patients with a first-episode psychosis, 81 patients were interviewed, either by client interviewers[2] or by non-client interviewers[3] using two questionnaires. The questionnaire scores obtained from two subgroups of interviewers were compared. In addition, the interviewees were asked whether it would have made a difference had they been interviewed by a client or by a non-client interviewer with regard to the truthfulness of their answers and the perceived course of the interview. The three client interviewers were asked whether their experience as a client influenced the truthfulness of the answers and the course of the interviews.

Results and conclusions

After their training the client interviewers appeared to be competent in interviewing techniques. There were no significant differences between the data obtained from the two subgroups of interviewers. However, the interviewees reported to feel more comfortable and to speak easier with client interviewers. No differences were found in the truthfulness of the answers given by the patients to the two types of interviewers.

The results indicate that involving client interviewers in interviewing members of their peer group is promising. This form of client participation yields interviews and data of a comparable quality level as when performed by non-client interviewers.

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1 "Client involvement" indicates involving people suffering from mental illnesses in different kinds of mental health activities.

2 "Client (interviewer)" refers to people who actually receive psychiatric services, or formally did (and who were involved in interviewing patients).

3 "Non-client (interviewer)" refers to independent professionals who have no experience as a mental health patient or as a professional caregiver (and who were involved in interviewing patients).

Objective

Client involvement in research remains a controversial topic (Hodgkin, 1996; Appleby, 2000; Trivedi, & Wykes, 2002). It is proposed that healthcare nowadays should be demand-driven (Rijckmans, Garretsen, Goor, van de, & Bongers, 2005) and from this viewpoint client involvement in mental healthcare seems to be obvious. Client involvement can occur in four different ways (Lecomte, et al.,1999): 1) planning, developing, registering and providing services, 2) advising and training professionals and managers, 3) looking after the interests of clients, and 4) exploring and evaluating the delivered services.

The following section addresses the goals of client involvement in research.

Client involvement in research

Involving clients in research serves four goals (Simpson, & House, 2002; Thornicroft, & Tansella, 2005). The first aim, as defined by Simpson, et al. (2003), is to improve the quality of care programs; they state that patients are entitled to high-quality services, and that clients should have the responsibility to judge the quality of the services provided. Clients achieve this goal by actively contributing to the planning and development of care programs and by taking part in (effect) studies. This results in clients giving advice to professionals about the improvement and development of both existing and planned services. In this way a new reality arises that combines insights from the client's perspective with professional insights, with the aim to improve the existing care services (Bracken, & Thomas, 2001).

The second aim focuses on the effect of participation in research on the recovery process of individual clients. This can be seen as a beneficial side-effect of the above-mentioned aim. Participating in research (in other words, performing meaningful activities) enhances empowerment and contributes positively to the recovery process of the clients involved (Liberman, Hilty, Drake, & Tsang, 2001).

The third goal is related to the positive influence of client involvement on the usefulness of Information and Communication Technology applications. The jargon used in social science applications (e.g. electronic patient files) is not easily accessible for most patients (Snoeker, et al., 2006). Clients can oblige software developers to make applications 'patient proof' such that patients can also use them and take advantage of them.

The fourth goal is to realize the assumed positive effect of client involvement on the quality of the data collected by client interviewers. Enhanced validity of the collected data, attributed to the more amenable atmosphere due to the presence of the client interviewer, has been reported (Simpson, et al., 2003; Clark, et al., 1999; Dietzen, & Bond, 1993; Faulkner, & Thomas, 2002). Clark, et al. (1999) conclude from their own research experience that patients answer more truthfully when peer group members, rather than professionals, interview them. The

objective of this study is to determine: 1) what influence do client interviewers have on the quality of the collected data and 2) on the course of the interviews?

Methods

In June 2004 two mental health institutes (in the south of the Netherlands) started a study on the effects of ACT on first-episode psychosis (Chapter 2). Within this study the patients filled in two questionnaires addressing Empowerment (Rogers, Chamberlin, Ellison, & Crean, 1997) and the Quality of Life (WHO-QoL-BREF) scale (de Vries, & van Heck, 1997).

Data were collected either by three client interviewers, or by two independent interviewers who had no experience as a mental health patient or as a professional caregiver for the present target group. The three client interviewers were selected from a group of (ex-)patients and all had some experience in activities related to client involvement, especially in representing patient's interests. The criteria for selection were a stable psychiatric mood, good communicative skills, sufficient emotional distance from their own disease state, and (when possible) a former member of the target group (i.e. patients who recently had a first-episode psychosis).This was objectivised by assessing the phase of recovery that the patients were in at that moment. All of the three candidates were at least in phase 3, "living with the disability" (Spaniol, Wewiorski, Gagne, & Anthony, 2002).

The clients were trained and familiarised with the two questionnaires. The training involved two sessions of 4 hours each and focused on general interviewing techniques and the content of the questionnaires. It was assumed that the clients had no previous knowledge of interviewing, and the teaching methods were specifically adapted to the clients (Dutch Guideline for Schizophrenia, 2005). The clients agreed to warn the staff if, for example, the training was going too fast or if too much jargon was being used. The training included theoretical and practical exercises, and visual aids were employed. The staff checked that the group maintained a good level of concentration, and frequent breaks were planned to avoid stress.

The second part of the training focused on the questionnaires. The content, the meaning of the questions, and the accuracy in completing the questionnaires were addressed. Also discussed was how to apply their specific experience as a (former) mental health patient. The client interviewers were instructed to inform the interviewees about their own background at the very beginning of the interview. In addition the client interviewers could support the interviewees to formulate the answers on the questionnaire. In this way the client interviewers can have a beneficial effect on the atmosphere during the interview, as well as on the quality of the information received.

Although the two questionnaires are structured, they may require different levels of support from the interviewers. For example, the patients may need more support on the Empowerment scale than on the Quality of Life scale, because the Empowerment scale consists of propositions which they may need to discuss before forming their final opinion.

The non-clients were already familiar with interviewing techniques, so only received training regarding the content of the questionnaires and how to use them.

All interviewers were asked to focus on completeness of the questionnaires and to check if all questions were answered.

To gain more insight into details of the interview and, based on this, to elucidate possible differences in the course of the interview, the first author held additional interviews with 20 randomly selected patients after they had been interviewed (from an anonymous/numbered list every fourth patient was selected for these interviews). These 20 patients were asked whether it would make a difference to the truthfulness of their given answers and/or the course and atmosphere of the interview had they been interviewed by clients or by non-clients.

Similarly, the three client interviewers were asked whether it makes a difference, and if yes, to what extent they think their experience as a client influences the truthfulness of the answers given by the interviewees and the course of the interviews.

Quantitative and qualitative analysis

The two subgroups of patients were compared for gender and level of education with a Mann-Whitney test. The data collected by both types of interviewers were also compared using a t-test. The internal consistency of the answers on the questionnaires of both sub-groups was determined by Cronbach's α. Then, the effect sizes (Cohen's Q) of the differences of the Cronbach's α between the two groups and the power were estimated.

In all analyzes a p-value <0.05 was considered statistically significant.

The quantitative data were analyzed with the software program SPSS version 15.0. The qualitative data were analyzed putting the free text answers of the 20 randomly assigned cases in an Excel sheet that was imported in SPSS text analysis for survey version 2.1. The 20 selected patients were proportionally divided over the 2 subgroups; 8 were interviewed by a client interviewer and 12 by a non-client interviewer.

Before running the analysis we defined a list of synonyms for expressions consisting of the same content, e.g. client=patient=consumer and mental illness=psychotic=schizophrenia. Then the software package categorized the free text answers. The interview data of the three client interviewers were analyzed manually because of the small numbers.

Results

In the present study 81 persons were interviewed: 24 by client interviewers and 57 by non-client interviewers. There were no significant differences between the two interviewed subgroups regarding gender distribution (p=0.24) and level of education (p=0.38).

The response rate was 100%; i.e. all patients who were invited took part in the interviews. Some appointments had to be rescheduled when patients forgot to attend, or cancelled the original appointment because they were unwell. Partly due to the support provided by the interviewers, nearly all the questionnaires were completed in full.

The interview data showed that the client interviewers made good contact with the patients, and the patients were prepared to give straightforward and detailed answers to the questions posed. The client interviewers applied their personal experience in various ways. For example, during the introductory phase they sometimes specifically explained the meaning of particular questions by illustrating them from, or by referring to, their own experiences. In other situations it was limited to a more global introduction in which their experience played a minor role.

All interviews followed the same procedure and began with an introduction about the aims of the research. In addition the client interviewers in their interviews explained their specific role in this. Most inter-viewees were positively surprised and this often resulted in an open and relaxed atmosphere. Patients felt free to interrupt and ask questions during the interview, and were not worried about giving a 'wrong' answer.

Quality of the data

The Empowerment scale was completed by 24 patients with client interviewers, and by 55 (out of 57) patients with non-client interviewers. For two patients the scale was not fully completed and these data were excluded from the analyses. The results of the two groups were comparable and, again, no significant differences were found (p=0.85) (Table 1).

The Quality of Life scale was completed by 24 patients with client interviewers, and by 57 patients with non-client interviewers. Again, the results of the two groups were comparable with no significant differences between them (p=0.89) (Table 1).

Table 1: Differences in the scores on the two questionnaires completed by client and non-client interviewers

		n	Mean score	Sign. p<0.05
Empowerment-scale	client-interviewer	24	2.81	Not significant
	non-client-interviewer	54	2.76	(p=0.85)
Quality of Life-scale	client-interviewer	24	90.25	Not significant
	non-client-interviewer	57	89.75	(p=0.89)

We estimated the internal consistency of the scores of the two questionnaires by measuring Cronbach's α to reveal any differences in internal consistency between the two subgroups of interviewers (Table 2).

The internal consistency of the subgroup of non-client interviewers was on nearly all (sub) scales higher (Cronbach's α on subscales of QoL ranged from 0.62 to 0.83, and overall Empowerment was 0.70) than the score on the internal consistency of the client interviewers (Cronbach's α on subscales of QoI ranged from 0.46 to 0.72, and overall Empowerment was 0.57). The effect sizes (Cohen's Q) of the differences in Cronbach's α between the two groups ranged from 0.21 to 0.40 (QoL scale) and from 0.11 to 0.30 (Empowerment scale). Due to the limited sample size of the present population these medium difference between the correla-tions could not be indicated with sufficient power (range 0.19-0.46 on the QoL scale, and 0.12-0.30 on the Empowerment scale).

Table 2: Differences in the internal consistency on the scores of the two questionnaires completed by client and non-client interviewers

Quality of Life-BREF	Cronbach's α client-interviewer (n=24)	Cronbach's α non-client-interviewer (n=57)
domain 1 physical health	0.64	0.82
domain 2 psychological health	0.67	0.77
domain 3 social relationships	0.46	0.62
domain 4 Environment	0.72	0.83

Empowerment	Cronbach's α client-interviewer (n=24)	Cronbach's α non-client-interviewer (n=55)
domain 1 Self-esteem/Self-efficacy	0.85	0.85
domain 2 Power/Powerlessness	0.50	0.33
domain 3 Community Activism and Autonomy	0.61	0.53
domain 4 Optimism and control over future	0.35	0.11
domain 5 Righteous anger	0.31	0.55
domain 6 Overall empowerment	0.57	0.70

After the interviews had taken place, 20 patients were asked if it would have made a difference to their answers if they had been interviewed by a client interviewer or by a non-client interviewer. Of these, 16 answered that this would have made no difference, and 4 patients said they would have given more truthful answers to client interviewers.

The client interviewers were of the opinion that truthfulness of the answers does not play a large role in this category of patients; they believe that these patients are too sick to 'cheat' and, moreover, are struggling with more serious matters every day.

Course of the interviews

According to the interviewees, the course of the interview does differ depending on who conducts the interview. The free text analysis resulted in two striking items: "feeling comfor-table" and "early phase". Of the 20 respondents, 13 said they prefer to be interviewed by a client interviewer because this makes them feel more comfortable; e.g. they are convinced that client interviewers have a better and quicker understanding of what they mean, especially for patients who are in an early phase of psychosis. The remaining 7 respondents said that the interview would be the same for them with either of the two types of interviewers.

Discussion and conclusions

Quality of the data

Literature shows some evidence that data acquired by clients enhance the validity of these data (Simpson, et al., 2003; Clark, et al., 1999; Dietzen, & Bond, 1993; Faulkner, & Thomas, 2002). In the present study, however, no enhancement emerged. The scores on the questionnaires (as acquired by the two types of interviewers) were very similar.

From an internal consistency analysis we conclude that non-client interviewers score better (but not statistically significant) on this item. Possibly, non-client interviewers had a better understanding of the content of the questionnaires.

Both the interviewees and client interviewers stated in interviews that the target group usually give truthful answers. Phenomena such as 'faking good' or 'faking bad' are not encountered by client interviewers: "members of this target group don't do that, especially not when client interviewers pose questions".

Course of the interviews

Interviewees stated that they found the atmosphere during the interviews supported by client interviewers pleasant and confidential and, therefore, not stressful.

Interviewees also indicated that the client's experience is of particular importance in the early phases of the recovery process, when the patient is not yet stable. In this stage it is easier for interviewees to explain what is happening because the client interviewers can immediately recognize what they mean.

In the opinion of the three client interviewers, the longer the interview lasts the more subjects emerge that probably would not have been addressed with non-client interviewers. Not every interview reflected the surplus value of the client interviewers, some more independent interviewees (n=14) completed the questionnaires without any additional advice or help.

General findings

Client participation in mental healthcare encompasses many different goals and new roles for clients to fulfil. Advantages and disadvantages have been reported. For example, Knight (2003) mentions one danger of working together with client colleagues: a relapse can occur and at that moment the role changes from colleague to patient. In the present study this also occurred once (one out of the three client interviewers relapsed once in a two-year period) and the person involved had to be admitted to the psychiatric ward of a local hospital; this had a negative effect on the continuation of the research process. Because of the mentioned disadvantages in literature and our own experiences, in this study we like to emphasise this outcome as a point of particular interest. A high level of awareness and sensibility could prevent relapses, despite the fact that in this case there was no obvious causal relationship between the relapse and fulfilling the job of a client interviewer.

Continuity also emerged as an important issue at other moments. Client interviewers find it important to get support in the logistical processes, even after two years. For example, they want a list of the clients they have to interview, specific deadlines for when to complete the interviews, and they appreciate having the appointments planned for them.

Grimwade (2002) warned about the vulnerable position of younger clients in this period of their life; they may become confused because of conflicting loyalties and interests. In the current study this was not an issue; none of the client interviewers (two of whom were about the same age as the interviewees) reported any problem related to conflicting loyalties and/or interests.

All client interviewers found interviewing to be a pleasant task; they found it challenging and exciting to contribute to scientific research. Meeting other people and speaking to them about this new role was a valuable experience for them. During the introductory phase the interviewees and the (sometimes present) carers asked interested questions and complimented the client interviewers for doing this job.

The client interviewers were very involved with this new work. They feel responsible and appreciate being taken seriously. It provides a new topic of conversation and gives them a feeling of pride and self-esteem.

The client interviewers reported that they had no feelings of relapse when being confronted with the stories of interviewees, even when they tend to remind them of their own periods of crisis (Whitfield, 1991).

Conclusions

This study indicates that the use of client interviewers in scientific research is promising, despite the fact that involving clients might seem a vulnerable situation due to the risk of relapses. Clients tend to complete the interviews fully and precisely, and the obtained scores on the questionnaires do not differ from those obtained by non-client interviewers. The results of the data obtained by non-client interviewers seem to have a better (but not statistically significant) internal consistency compared with the data of the client interviewers.

Interviewees judged the course of the interviews conducted by client interviewers as being better and more pleasant than those conducted by non-clients.

Most interviewees state that, especially in the early stages of their recovery process, there are benefits in using client interviewers.

References

- Appleby, L (2000). A new mental health service: high quality and user-led. *Br J Psychiatry*, 177: 290-291.
- Bracken, P. & Thomas, P. (2001). "Postpsychiatry: a new direction for mental health". *BMJ*, 322: 724-727.
- Clark, C.C., Scott, E.A., Boydell, K.M. & Goering, P. (1999). Effects of client interviewers on client-reported satisfaction with mental health services. *Psychiatric Serv*, 50: 961-963.
- Dietzen, L.L. & Bond, G.R. (1993). Relationship between case manager contact and outcome for frequently hospitalized psychiatric clients. *Hosp Commun Psychiatry*, 44.9: 839-843.
- Faulkner, A. & Thomas, P. (2002). User-led research and evidence-based medicine. *Br J Psychiatry*, 180: 1-3.
- Grimwade, J. R. (2002). Child consumer and parent/carer involvement, *BMJ*, 2002;325:1265
- Dutch Multidisciplinary Guideline for Schizophrenia (Multidisciplinaire richtlijn Schizofrenie) (2005). Onder auspiciën van de Landelijke Stuurgroep Multidisciplinaire Richtlijnontwikkeling in de GGZ.
- Hodgkin, P. (1996). Medicine, postmodernism, and the end of certainty. *BMJ*, 313: 1568-1569.
- Knight, A. (2003). Employing users who turn back into patients is difficult. *BMJ*, 326:449.
- Lecomte, T., Wilde, J.B. & Wallace, C.J. (1999). Mental health consumers as peer interviewers. *Psychiatric Serv*, 50(5): 693-695.
- Liberman, R.P., Hilty, D.M., Drake, R.E. & Tsang, H.W.H. (2001). Requirements for multidisciplinary teamwork in psychiatric rehabilitation. *Psychiatric Serv*, 52:1331-1342.
- Rijckmans, M.J.N., Garretsen, H.F.L., Goor, L.A.M., van de & Bongers, I.M.B. (2005). Key concepts of demand-driven health care; an approach based on client's need. *Med Law*, 24(3), 463-477.
- Rogers, E.S., Chamberlin, J., Ellison, A.L. & Crean T. (1997). A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatric Serv*, 48:1042-1047.
- Simpson, E.L. & House, A.O. (2002). Involving users in the delivery and evaluation of mental health services: systematic review. *BMJ*, 325:1265-1267.
- Simpson, E.L., Barkham, M., Gilbody, S. & House, A. (2003). Involving service users as service providers for adult statutory mental health services. *The Cochrane Database of Systematic Reviews*, Issue 4. Art. No.: CD004807.
- Snoeker, B., Bogaard, van den, J., Jacobs, H., Garretsen, H. (2006). Zinloze herhaling van informatie? Een exploratieve studie naar de informatieoverdracht binnen de GGZ. [Useless repetition of information? An explorative study on information processing in mental health care]. *Maandblad Geestelijke volksgezondheid*, 61:112-119.

- Spaniol, L.S., Wewiorski, N.J., Gagne, C., & Anthony, W.A. (2002). The process of recovery from schizophrenia. *Int J Psychiatr,* 14(4),327-336.
- Thornicroft, G. & Tansella, M. (2005). Growing recognition of the importance of service user involvement in mental health service planning and evaluation. *Epidemiologia e Psichiatria Sociale,* 14, 1-3.
- Trivedi, P. & Wykes, T. (2002). From passive subjects to equal partners: qualitative review of user involvement in research. *Br J Psychiatry,* 181, 468-472.
- Vries, J. de, & Heck, G.L. van (1997). The World Health Organization quality of life assessment instrument WHO QOL-100: Validation study with the Dutch version. *Eur J Psycholog Assess,* 13(3), 164-178.
- Whitfield, C. (1991). Co-dependence: Healing the Human Condition: The New Paradigm for Helping Professionals and People in Recovery. *Health Communications, Inc.*

CHAPTER 5

EFFECTIVENESS OF ASSERTIVE COMMUNITY TREATMENT VERSUS CARE AS USUAL IN EARLY PSYCHOSIS

Results of a two-year quasi-experimental outcome study

Abstract

Objective

Assertive Community Treatment (ACT) is described as a team treatment model designed to provide assertive, outreaching, comprehensive, community-based, rehabilitation-oriented and supportive psychiatric services for people with severe mental illness. ACT was shown to have superior outcome results when compared to care as usual (CAU). This study explores differences in outcome between ACT and CAU when provided to a new target group, i.e. patients suffering from a first-episode psychosis. Two Dutch mental healthcare institutions participated; one institution provided ACT (n=105) and the other provided CAU (n=44).

Methods

To establish differences between the outcome of the two services over a 2-year period, outcome areas were defined and data concerning these areas were obtained from client files.

Results and conclusions

The outcome of this study shows that ACT and early psychosis yields an effective match. Most of the ACT outcome measures showed a significantly better outcome compared with CAU.

Introduction

Assertive Community Treatment (ACT) is a well-known evidence-based practice that is frequently applied because of its positive impact on, in particular, the target group of severely mentally ill persons (Marshall, & Lockwood, 1998; Drake, et al., 2001; Dixon, 2000; Teague, Bond, & Drake, 1998; Mueser, Bond, Drake, & Resnick, 1998). In several countries ACT has proven to be an effective and efficient treatment model for the group of patients mostly referred to as 'Severe Mentally Ill' (SMI). The model was designed in the USA in the 1970s by Stein and Test. From the beginning they intended to create a model that offers SMI patients an alternative to hospitalization; the target group left the hospital and learned how to live in the community. Typical features of this model are: the attitude of the professionals is proactive and assertive, treatment takes place in the community, a multidisciplinary team is responsible for a group of patients, and the team delivers all the services required.

Why ACT in early psychosis?

In early psychosis it is considered important to intervene during the critical period (i.e. the first 3-5 years) and start treatment immediately after the first positive symptoms appear. This approach results in a more favourable outcome and has a positive effect on the long-term course of the illness (Jørgensen, et al., 2000; Petersen, et al., 2005; Singh, & Fisher, 2005; Verhaegh, Bongers, Kroon, & Garretsen, 2008a; Wunderink, & Alexander, 2006). Having established the beneficial effects of ACT in SMI patients, it is feasible that persons with early psychoses may also benefit from ACT (Burns, Creed, Fahy, Thompson, & Tyrer, 1999; Jørgensen, et al., 2000; Rosenheck, & Neale, 2001).

Patients with a first-episode psychosis who are provided with ACT after a 'short Duration of Untreated Psychosis' (DUP) receive multidisciplinary and integrated care from the very beginning, so that positive results can be expected (Archie, 2006; Jørgensen, et al., 2000; Pelosi, & Birchwood, 2003). Both the number and duration of crises, and related hospitalizations, are expected to decrease, leading to increased patient satisfaction. Moreover, by helping to prevent crises and avoiding hospitalizations, ACT may have a positive effect on long-term psychosocial and cognitive functioning, thereby having a positive influence on cost-effectiveness on the longer term (Cuddeback, Morrissey, & Meyer, 2006; Yang, et al., 2005).

Thus, from the literature and from our own clinical experience during the last 3 years we know approximately what percentage of the total group of clients will probably have a relapse, but we do not know specifically who will relapse (Wiersma, Nienhuis, Slooff, & Giel, 1998; Vlaminck, 2003; Addington, Addington, & Patten, 2007). For this reason we chose to apply ACT to the total group of clients. Events in the first 3-5 years after the appearance of the first positive symptoms

of psychosis (the critical period) determine the future course of the recovery process and functioning of the client (Spencer, Birchwood, & McGovern, 2001; McGlashan, 1999; Scully, Coakley, Kinsella, & Waddington, 1997).

A positive correlation has been shown between improved outcome of treatment and a shorter DUP (Marshall, et al., 2005; McGlashan, 2005; McGorry, Nordentoft, & Simonsen, 2005; McGorry, & Pelosi, 2004; Norman, Lewis, & Marshall, 2005; Perkins, Gu, Boteva, & Lieberman, 2005). An assertive approach of an ACT team towards referred clients could also be a meaningful feature in the aim to shorten the DUP (Nordentoft, et al., 2008). Furthermore, ACT has been shown to be cost-effective; due to decreasing usage of clinical services the total ACT costs were 20% lower than 'care as usual' (McGorry, Killackey, & Yung, 2007; Jeppesen, et al., 2005). In our recent study we concluded that ACT is a cost-effective treatment (Verhaegh, 2008b, in press). Nevertheless, some criticize ACT for being too costly or too intensive, and/or because not all studies show the same effect sizes. The latter can probably be attributed to poor model fidelity in the experimental condition and to the improved quality of the examined 'care as usual' (Billings, et al., 2003; Killaspy, et al., 2006). Regarding the high costs of ACT, intensive treatment with a caseload of 1:10 applied in times of economic recession has provoked criticism (Fenwick, & Byford, 2005, Test, & Stein, 2001; Byford, et al., 2000); however, this does not prove that ACT is not cost-effective on the long term. Finally, some argue that resources should not be spent too quickly and to the full extent; a stepped-care approach is suggested by these critics. When it becomes obvious that low-intensity care is not (sufficiently) effective, it then becomes justified to implement more intensive alternatives. This way of assigning care avoids taking responsibility away from the client and ensures, for example, hospitalization in the client's own surroundings (Davison, 2000).

Importance of model fidelity

Both the founders and those who adapt ACT emphasize the importance of fidelity in implementing ACT; a positive outcome is attributed to full implementation of the original model (Burns, et al., 2002; Drake, et al., 2001; McGrew, & Bond, 1995a; Priebe, et al., 2004; Test, & Stein, 2001; Weaver, Tyrer, Ritchie, & Renton, 2003). When applying ACT to a new target group it has to be precluded that the outcome (or absence thereof) can be attributed to poor fidelity (Kuipers, Holloway, Rabe-Hesketh, & Tennakoon, 2004).

Despite all this knowledge, in the Dutch situation we have no evidence that ACT and early psychosis is an effective match. Therefore, the present study addresses the following research question: What effect does ACT (provided in and around the city of Eindhoven) have on patients who suffer from early psychoses compared to a similar group of clients who received care as usual (provided in and around the city of Tilburg) over a 2-year treatment period?

Methods

In July 2004 a mental healthcare organization in the southern part of the Netherlands (Mental Healthcare Eindhoven) started to treat a group of clients according to the principles of ACT. The target group consists of all customers with a first psychotic episode (excluding substance-induced psychotic disorders). The catchment area comprises 500,000 inhabitants of whom 210,000 live in a city.

Study design

The design used is quasi-experimental. The control group was located in Tilburg where CAU was provided and the experimental group was located in Eindhoven and received ACT.
In the present study, random assignment to each condition was not possible because of the experimental treatment provided, and because some patients were already receiving CAU.

Everyone who received specialised mental healthcare for a first-episode psychosis was potentially included in the study, with the exception of patients who had drug-related or postpartum psychoses. The patients were selected based on the DSM-IV codes.

Target group

The members of the target group are mostly in the age group 18-35 years and recently had their first-episode psychosis (Table 1). The target group comprised 149 patients: 105 in the experimental group and 44 in the control group. The average age of the total population was 26 years; 76% was younger than 35 years. The age of the patient was determined on the date that ACT and CAU commenced, i.e. shortly after remission of the client's first psychosis. No statistical significant differences were found in sex and age. DSM-IV classifications between the two groups show some differences. The control group consists of more patients diagnosed with schizophrenia or subtypes (38%) compared to the experimental group (25%). In the other prominent group of patients, diagnosed with Psychotic Disorder NOS, we see a reverse distribution, 32% in the control group and 42% in the experimental group.

At baseline the control group scored higher on the job/school characteristic. Of the control group 45% had a job or went to school versus 34% of the experimental group. At baseline, more patients from the experimental group lived on their own (51%) than patients in the control group (38.6%). More patients in the control group lived with their parents (38.6%) than members of the experimental group (31%). More members of the experimental group were looking for an independent living facility (10%) than in the control group (2.3%). In the experimental group 8% was admitted or lived in a house for sheltered living compared with 20.5% in the control group. At baseline the control group showed a similar level of "good/ moderate social adjusted" (92%) as did the experimental group (93.3%).

Inclusion criteria at baseline were:

- client suffers from a first-episode psychosis;
- client recently (in the last year) had first positive symptoms;
- clients are diagnosed with psychotic disorders, including schizophrenia and all its sub-types;
- client adequately understands/speaks the Dutch language.

Clients suffering from organic psychiatric disorders and clients with a mental retardation co-morbidity (IQ <80) were excluded.

Table 1. Characteristics of the target groups: ACT (experimental) group and the CAU (control) group at baseline

	ACT (n=105)	CAU (n=44)
Gender		
Male	82 (78.1%)	31 (70.5%)
Female	23 (21.9%)	13 (29.5%)
Age (years)		
Mean	26.3 (SD 8.1)	25.3 (SD 8.5)
Range	16-52	17-54
DSM-IV		
295.xx[1]	26 (24.8%)	17 (37.7%)
298.9[2]	44 (41.9%)	14 (31.8%)
DUP	Median = 3 months	-
Job/school		
Yes	8 (8%)	9 (21%)
With IPS or support	27 (26%)	11 (24%)
No (occasionally)	39 (37%)	14 (31%)
Not ready	30 (29%)	10 (24%)
Housing		
Yes, own	53 (51%)	17 (38.6%)
Yes, with parents	32 (31%)	17 (38.6%)
Looking for own	10 (10%)	1 (2.3%)
No, admitted/sheltered	9 (8%)	9 (20.5%)
Social adjusted		
Yes	64 (61.9%)	31 (70%)
Moderate	33 (31.4%)	9 (21%)
No, cause trouble	7 (6.7%)	4 (9%)

[1] Schizophrenia and all subtypes
[2] Psychotic Disorder, not otherwise specified

ACT: the experimental condition

Most patients in the study were included via a crisis intervention service within 6 weeks after the appearance of their first positive symptoms; this means that the DUP is very short (at baseline the median DUP score was 3 months, and after 4 years it was 2 months). The experimental group was included over a 2-year period which started in 2004 with a group of patients who had had their first-episode psychosis within one year before the moment of inclusion. This concerned 30 patients that had been referred from different locations of the municipal health authority. Most of these clients were well acquainted with the psychiatrist in the ACT team. In the following 2 years the group reached its maximum capacity of 105 clients.

ACT and provided services

Within the specific ACT organizational context, the ACT team aims to provide services that are preferably evidence-based and, if not available, based on best known practices and professional experiences. The main starting point is the recovery process of the client. All team members are experienced and trained (Boston Rehabilitation, Rehab '92 methodology) to meet the needs of the clients and carers, and contribute to their recovery process using specific communication techniques and rehabilitation-based interventions (readiness assessment, Liberman modules). Shared values include: easily accessible services/staff, and communication on an equal basis between team members, as well as between professionals and clients/carers.

ACT offers a multidisciplinary team approach and provides integrated intensive care (treatment, plus support geared to patients with co-morbid disorders) in a pro-active way. Generally there is a low case load (staff/patient ratio of 1:10 or less) (Verhaegh, 2008a). The ACT team provides most of the services directed at all dimensions of daily life. Most services are provided within the community, and seldom within the hospital. Outside of normal working hours, the ACT team is supplemented by a crisis intervention service (including a shared electronic patient file system and crisis intervention plan). During the weekend one of the ACT staff can be reached by phone. The entire ACT team has daily briefings (Clark, et al., 1998; Jørgensen, et al., 2000; Latimer, 1999; Lehman, et al., 1999; Verhaegh, 2008a)

The ACT team delivers the following services:
Case management: this focuses on social functioning and role fulfilling, observing the (side-) effects of medication, compliance with medication, intervening in family and carer systems, and providing crisis intervention techniques, psycho-education and medication.

Cognitive Behavioural Therapy (CBT) aims to replace or transcend the inadequate thoughts or behaviours with more realistic and useful ones. A frequently applied variant of CBT for psychotic patients is the 'unravelling of thoughts and ideas' (in Dutch: 'gedachten uit pluizen') (Gaag, 2005).

Psycho-education in family and client groups aims to increase patients' and carers' knowledge and understanding of illness and treatment. It is assumed that increased knowledge enables people with psychosis to cope more effectively with their illness. Psycho-education is provided separately for carers and patients in order to allow maximum attention to be paid to specific demands and issues.
The ACT provides treatment elements of an integrated Double-Diagnosis treatment model. This means an integrated treatment for both autonomous, but interacting, disorders (e.g. psychiatric disorder and substance abuse).

Vocational training and school support intends to support patients in choosing, gaining and maintaining a job, education or day activities starting from an evidence-based practice (individual placement and support, and supported education techniques).

The ACT Housing support professional focuses on providing patients with a place to live of their own choice. He operates in social networks and negotiates with housing companies, parents and patients to find the best-fitting solution to the housing demand of the patient. The importance is obvious because homelessness often leads to hospitalization. All kind of tasks related to housing are of the housing specialist's concern, e.g. financial, hygiene, nutritional, and furniture issues.

The peer group worker (Individual and group peer support) is a professional, fully responsible and informed member of the team. He operates from his own experiences combined with techniques on how to apply the experiences in a good balance between maximum involvement on the one hand, and a professional distance on the other. The peer group worker provides a low-level access and focuses on all kinds of thought, anxieties, and uncertainties related to the patient's disorders.

Pharmacotherapy is a key element in ACT treatment. The psychiatrist always first connects to the patient (and their carers) and starts from the present medication policy and professional guidelines. Except for emergency situations, pharmacotherapy is primarily based on an intention to consensus.

CAU, the control condition
Clients are generally referred by a general practitioner or via crisis intervention services to a psychiatrist and/or a social psychiatric nurse. Together, they draw up a treatment plan and thereafter most patients receive low-intensive outreach care. If problems should arise, the patient or the community/carers or a professional staff member can request that the care be upgraded. This means that some patients receive temporary additional out-patient services, such as cognitive behavioural therapy or family treatment. In case those treatment

arrangements also prove to be insufficient, day treatment or inpatient care (crisis intervention) is available. Some patients also receive additional help from the local authority (e.g. to find a suitable job or home), or parallel treatment for their substance abuse. In CAU the following are not available: peer support, dual- diagnosis treatment, housing support, vocational training and school support. All clients of the control group were already receiving treatment at the moment of inclusion (October 2006). These patients were included from an electronic database, and no additional clients were added to the database after October 2006.

When comparing ACT with CAU some similarities emerge as well as major differences. First of all, the focus on a homogeneous target group (i.e. clients in their early phase of psychosis) makes ACT a specialised facility with specialists trained for this specific target group. Their team approach and vision is prominent: assertive, outreach and (from the very beginning) focused on gaining and re-gaining social roles (e.g. work, friends, family and school) and responsibilities in society. Only when it is unavoidable is a client admitted to a clinic for a short period of time. Other major differences between ACT and CAU are the organization of the treatment model, and the presence of specialised interventions and knowledge (e.g. IPS and school support, double-diagnosis treatment, peer support, housing support).

Fidelity of both treatment models

The differences between the two models were characterized by using the scores on the Dartmouth ACT Scale (DACTS) (Teague, Bond, & Drake, 1998) that establishes the fidelity level of the two treatment conditions (Verhaegh, 2008a). The rationale for acquiring DACTS scores is based on a UK study that showed less effect differences between ACT and CAU compared with American studies, partly due to a higher fidelity level among the CAU group (Burns, et al., 2002).

Data collection

From ACT effect studies (Killaspy, 2006; Nordentoft, 2003; Weaver, 2003) we collected outcome measures and used them for the present study: numbers and duration of hospitalization, alcohol/drugs use, suicidal behaviour, social adjustment (adaptation of the person to the social environment), treatment/medication compliance, work/school rates, and housing. In addition we obtained:

- GAF scores

Global Assessment of Functioning (GAF) is a single-item rating scale for clinicians to rate the overall psychosocial functioning of patients with 10 anchor points and continuous scores ranging from 1 to 100 (Endicott et al., 1976).

- CGI scores

The Clinical Global Impression scale (CGI) is designed to assess the global severity of illness, and change in the clinical condition over time. The Dutch version we used consists of two global (7-point Likert scales) subscales: 'Severity of illness' (scores from: 1, "normal, not sick" up

to 7, "very severely ill") (Nolen, www.tijdschriftvoorpsychiatrie.nl/meetinstrumenten/download.php?id=29).
Data were assessed at the beginning of the treatment (usually 1 to 3 months after the first-episode psychosis) and after a 2-year treatment period. In both conditions we used data from medical files.

The data search of the *control group* was conducted by a research assistant and the first author operating together as a team. Using this method there were no differences in the way data were collected, or in the way data were interpreted and scored. After this process, we checked the accuracy and completeness of the data, and made corrections as required based on telephone calls with the responsible professionals.

The data search of the *experimental group* was conducted by the same team based on the electronic files system. Again, the method was characterized by intensive cooperation and a two-way checking system. All interpretations and scores were seen by the research assistant and, in the presence of differences, in all cases a solution was found or consensus established.

In addition to these data in both conditions, we asked the professionals to fill out (retrospectively) a form consisting of a GAF score and a CGI score. Those clinical judgements (at baseline, and at 1 and 2 years) of the professionals were intended to provide additional clinical relevance and 'backbone' to the collected file data. Scoring the GAF is considered routine work because it is part of completing the DSM-IV diagnosis. All professionals received similar training to enhance the reliability of their diagnosis. Concerning the CGI scores, the professionals received an instruction guide prepared by the first author; in this way we enhanced the inter-rater reliability of the control group data. In the experimental group, the team psychiatrist completed all the questionnaires. In the control group 9 persons were involved in completing 44 questionnaires.

Based on national and international studies we hypothesized that, for all the mentioned measures, better outcomes would emerge for ACT.

Statistical analyses
Analyses were performed using SPSS 14.0. The Wilcoxon signed ranks test was used to test differences between outcome variables at baseline and at 2-year follow-up between the two target groups. We chose to present the results in detail in order to retain important empirical information and tendencies. Due to the relatively small numbers of patients in this study a low statistical power was expected; therefore we chose to dichotomize ordinal level variables (Table 2).

Table 2. Variables and dichotomization

Suicidal behaviour		Social adjustment		Compliance treatment		Compliance medication		Suicidal behaviour		Drugs/ Alcohol		Work/ School		Housing	
committed suicide dangerous	passing issue no issue	No, cause trouble	moderate no yes	moderate, needs support good	no compliance	Moderate, need support Good	no compliance	committed suicide dangerous	issue passing issue no issue	Yes, + diagnosis Yes	Occasionally No, does nog use	with IPS or support Yes	not ready No (occasionally)	yes, with parents looking yes, own	sheltered no, admitted,
Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No

The one-way repeated measures test was used to explore differences in improvement between the groups (GAF and CGI scores) over the 2-year period (controlled for different baseline scores). The independent sample T-test was used to explore differences between the groups over the 2-year period when only 2 measurements were available.
For variables on an ordinal level, logistic regression was performed to test differences in improvement between the two groups over the 2-year study period (controlled for different baseline scores). The level of significance in all tests was set at a p-value <0.05.

Results

Fidelity

Each year the fidelity of the offered treatment was measured using the DACTS (Teague, Bond, & Drake, 1998). This resulted in outcomes indicating that ACT was fully implemented (2004, 3.5; 2005, 4.3; 2006, 4.2) (Verhaegh, 2008a). Because the treatment conditions for the control group over the 2-year period were relatively stable, the DACTS of the CAU was determined only once (Table 3). Based on the numbers of patients in each subgroup, we calculated a weighted average total fidelity score for CAU of 2.4. A score of 1.0 to 3.0 indicates a low degree of implementation (Salyers, Bond, Teague, Cox, & Smith, 2003).

Table 3. DACTS scores[1] for the ACT and CAU groups

	ACT group 2004	ACT group 2005	ACT group 2007	CAU group 2008
Team structure	4.2	4.6	4.4	2.4
Organization	3.6	4.8	4.4	2.9
Services	2.7	3.5	3.7	1.7
DACTS score[2]	3.5	4.3	4.2	2.4

[1] DACTS score range is 1–5; a higher score indicates a higher fidelity
[2] The total score is the mean of 3 sub scores (team structure, organization and services)

Global Assessment of Functioning and Clinical Global Impression (Table 4)

Over the 2-year period the GAF score of both groups improved significantly. The mean score of the ACT group increased from 40.5 at baseline to 50.9 after 2 years ($p<0.0005$). In the control group the score increased from 44.2 at baseline to 48.1 ($p=0.009$) after 2 years.
The mean baseline GAF score was significantly higher in the control group compared to the experimental group (44.2 vs. 40.5, $p= 0.02$); after 1 and 2 years the differences in GAF scores between the two groups were smaller and were not significant.
The improvement in GAF score between the groups over the 2-year period (controlled for the different baseline scores) was significant in favour of the ACT patients (Wilk's Lambda = 0.92, $F (2, 143) = 5.98$, $p= 0.003$, multivariate partial eta squared = 0.077). The test shows that there was a linear-type improvement over time.

The CGI improved (i.e. a decrease in score) over the 2 years. Both groups showed a significant improvement on the CGI scale: i.e. the scores of the ACT group decreased from 4.60 to 3.10 and those of the CAU group from 4.09 to 3.39 (both $p<0.0005$).
The mean baseline CGI score was significantly lower (= better condition) in the CAU group compared to the ACT group (4.09 vs. 4.60, $p= 0.008$); after 1 and 2 years the differences in CGI scores between the two groups were smaller and not significant.
The improvement in the CGI score between the groups over the 2-year period (controlled for the different baseline scores) was significant in favour of the ACT patients (Wilk's Lambda = 0.91, $F (2, 139) = 6.95$, $p= 0.001$, multivariate partial eta squared = 0.091). The test shows that there was a linear-type improvement over time. From the eta score we conclude that the effect size of these improvements (GAF 0.92 and CGI 0.91) is moderate (Cohen, 1988).

Table 4. Scores and differences on the GAF and CGI at baseline, and at 1 and 2 years

	GAF at baseline	GAF at 1 year	GAF at 2 years	One-way repeated measures ANOVA
ACT (n=102)	40.5 (SD 11.9)	45.7 (SD 14.5)	50.9 (SD 14.5)	F = 5.98
CAU (n=44)	44.2 (SD 6.0)	46.9 (SD 7.9)	48.1 (SD 6.0)	P= 0.003
	CGI at baseline	CGI at 1 year	CGI at 2 years	One-way repeated measures ANOVA
ACT (n=98)	4.60 (SD 1.22)	3.63 (SD 1.37)	3.10 (SD 1.41)	F = 6.95
CAU (n=44)	4.09 (SD 0.99)	3.57 (SD 1.13)	3.39 (SD 1.47)	p= 0.001

Significance level $p<0.05$

Number and duration of admissions

After their first crisis 39% of the control group has a relapse at least once (mean=2.5) in the following 2 years. In the experimental group this percentage is 26% (mean=1.7). The average duration of an admission in the control group is 77 days, in the experimental group this number is 64 days (Table 5.1). The overall use of beds over a 2-year period is significantly less for ACT (T-test, $p=0.014$).

Table 5.1. Outcome ACT versus CAU at baseline and after 2 years

	CAU (N=44) At baseline	ACT (N=105) At baseline	CAU (N=44) After 2 years	ACT (N=105) After 2 years
Admissions				
# Relapsed clients (admitted)	-	-	17 (39%)	27 (26%)
Total number of crises (admitted)	-	-	42	46
Total number of admission days	-	-	3234	2944
Average duration of admission	-	-	77 days	64 days
Drugs use				
yes + DSM diagnosis	9%	12%	7%	17%
yes	30%	18%	15%	15%
occasionally	18%	12%	21%	11%
no	43%	58%	57%	57%
Alcohol use				
yes + DSM diagnosis	11%	5%	9%	3%
yes	14%	16%	11%	8%
occasionally	23%	18%	32%	17%
no	52%	61%	48%	72%

Alcohol and drug use

Alcohol abuse in the CAU group (Table 5.1) did not decrease over the 2-year period (p=0.82). In the ACT group there was much less alcohol abuse but the improvement was not significant (p=0.16).

There was no significant difference in the extent of improvement between the groups for alcohol use over the 2 years, controlled for a significant baseline difference (logistic regression, Wald 0.006, p=0.939).

For drug abuse, the control group showed a greater improvement over 2 years (p=0.003) than the experimental group (p=0.47). Differences between the two groups for drugs use were negligible at baseline (p=0.26) and also after 2 years (p=0.36). A significant difference (controlled for baseline difference) in the extent of improvement between the groups for drug use over the 2 years was found in favour of the CAU group (logistic regression, Wald 5.013, p=0.025).

Table 5.2. Outcome of ACT versus CAU at baseline and after 2 years (continued)

	CAU (N=44) At baseline	ACT (N=105) At baseline	CAU (N=44) After 2 years	ACT (N=105) After 2 years
Suicidal behaviour				
no issue	66%	65%	77%	87%
issue, passing	27%	27%	18%	10%
issue, dangerous	7%	8%	5%	2%
committed suicide	0%	0%	0%	1%
Social adjustment				
yes	70%	61.9%	70%	83%
moderate	21%	31.4%	25%	11%
no	9%	6.7%	5%	6%
Compliance, treatment				
good	45.5%	55%	48%	66%
moderate, support	34.1%	31%	36%	26%
no compliance	20.5%	14%	16%	8%
Compliance, medication				
good	52%	65%	48%	50%
moderate, support	34%	22%	36%	28%
no compliance	14%	15%	16%	16%
no medication	(n=0)	(n=1)	(n=0)	((n=7)
Job/school				
Yes	21%	8%	21%	26%
with IPS or support	24%	26%	7%	23%
No (occasionally)	31%	37%	36%	27%
not ready	24%	29%	36%	24%
Housing				
yes, own	38.6%	51%	46%	54%
yes, with parents	38.6%	31%	32%	31%
looking for own	2.3%	10%	0%	5%
no, admitted, sheltered	20.5%	8%	23%	10%

Suicidal behaviour (Table 5.2)

In both groups there was a considerable decrease in suicidal behaviour over the 2 years (CAU $p<0.005$ and ACT $p<0.005$). The groups showed no differences when compared at baseline (T-test 1-sided: $p=0.08$) and after 2 years (T-test 1-sided: $p=0.11$). After 2 years the ACT group showed less suicidal behaviour compared to the control group (one member of the ACT group committed suicide). There were no significant differences between the two groups in the extent of improvement (controlled for baseline differences) over 2 years (logistic regression, Wald 0.60, $p=0.806$).

Members of the CAU group showed no increase in social adjustment over the 2 years ($p=0.64$), whereas the experimental group did ($p<0.005$). No significant differences between the two groups were found in the extent of improvement (controlled for baseline differences) over 2 years (logistic regression, Wald 0.23, $p=0.880$).

Treatment and medication compliance

Treatment compliance in the control group did not increase over 2 years (p=0.32), whereas in the experimental group there was significantly better compliance with the treatment (p=0.01). At baseline, the differences between the groups for treatment compliance were negligible (p=0.24); after 2 years the ACT group was significantly more compliant with treatment than the CAU group (p=0.04).

Concerning compliance to medication: the control group shows no significant improvement over 2 years (p=0.32) whereas the compliance of the experimental group becomes (not significantly) worse (p=0.21). The differences between the two groups for medication compliance were negligible at baseline (p=0.53) and also after 2 years (p=0.78).

No significant differences between the two groups were found for the extent of improvement (controlled for baseline differences) over 2 years (logistic regression, Wald 0.907/0.001, p=0.341/0.974).

Work/school

In both conditions work and school rates improved over 2 years. The improvement in the control group was not significant (Wilcoxon signed ranks test, 1-sided, Z=1.671, p=0.05), whereas in the experimental group work/school rates improved significantly (Wilcoxon signed ranks test, 1-sided, Z=3.622, p<0.005).

The differences in the extent of improvement between the two groups over the 2 years (controlled for baseline differences) were significantly better for ACT (logistic regression, Wald 9.21, p=0.002).

Housing

In the domain of housing there were no changes over time for both groups (CAU p=0.91, and ACT p=0.62). There were no differences between the two groups on the Wilcoxon signed ranks test (Z=0.116, p=0.91), and no differences over the 2 years controlled for baseline differences (logistic regression, Wald 1.270, p=0.260).

Discussion and conclusions

Discussion

ACT is the most researched evidence-based treatment model and has been proven (cost-) effective for the group of most severely mentally ill patients. In this study we investigated whether this treatment model could also be effective for the target group of patient who suffer from a first- episode psychosis.

Is ACT effective?

Several indications emerged to support that ACT is an effective match for this target group. We found an overall effect tendency that there is more improvement in the ACT condition over a 2-year treatment period; however, not all effects were significant. When comparing the two target groups in general there is a better outcome for the ACT condition.

Compared to the control group, significantly better outcomes were found for number and duration of admissions, and work/school rates. For the outcome drug usage, the CAU group scored better than the ACT group. This result can only partially be attributed to CAU because drug addicted patients are usually referred to a specialized external organization for substance abusers. We have no explanation for the increased rate of drug use in ACT, despite the double diagnosis services.

On the outcome areas social adjustment, alcohol usage, and treatment compliance ACT scored better, but the differences were not significant. For housing no difference was found between the two groups over a 2-year period. Concerning suicidal behaviour both groups scored well. Despite one suicide in the experimental group, on average, ACT scored better. For medication compliance, ACT had a decreased effect over two years. This might be explained by a stronger alliance with the patient expressed in greater treatment compliance; poorer medication compliance might be the price paid for better treatment compliance.

We intended to give the above-mentioned outcome measures a clinical relevance and 'backbone'. When looking at the outcomes of the GAF and CGI we must conclude that, on those measures, there is a considerable (significant with moderate affect sizes) difference between the two groups.

In both conditions there are considerable improvements. ACT shows larger differences between baseline scores and scores at the end of the treatment period, and also shows the same extent of improvement in the second year as in the first year. This probably indicates a further improvement in function after 2 years of treatment. At baseline, CAU shows significantly lower scores on CGI and higher scores on GAF indicating that patients function better at the start of that treatment. A reason for this could be the later inclusion in the CAU group due to a longer transfer period between the acute care service and the target group. From another viewpoint,

or explained as a positive effect of ACT, this means that ACT patients are included relatively quickly after their first-episode psychosis.

Fidelity in CAU

In the present study, by measuring the fidelity of both models it became clear that CAU has a low ACT fidelity. It also becomes clear that, although some of the provided services have similarities, for some essential characteristics the two models show major differences. For this the outcome found in CAU cannot be attributed to the existence of ACT features. This also means that the differences found in outcome show no underestimation because of the existence of ACT features in CAU (Burns, et al., 2002).

The results presented here show that typical ACT features are effective services to increase the clinical condition of young patients, and also demonstrate that psychosocial functioning improves (significantly) more than in CAU. For Dutch clinical practice this means that ACT in early psychosis is no longer without obligations and, in general, this outcome makes a positive contribution to the current evidence regarding the care for patients suffering from an early psychosis.

Limitations of the study

The data that we obtained were not entirely complete because the file/recording system of the CAU changed to an electronic system; during the transfer period some weeks showed a lack in the continuity of information. We later checked for correctness by asking professionals if the collected data were correct and complete. In both conditions (experimental and control) we did not have full insight regarding the external admissions of patients, e.g. ward of a general hospital. We have no indication whether this has biased the data.

In spite of our defining 'suicidal behaviour' the data for this area were biased, probably due inconsistent use of the definition or the terms. During the data collection process we noticed an under-registration of suicidal incidents. Professionals tend to interpret suicidal behaviour as 'temporary risky behaviour'.

During the 2 years of treatment the ACT condition evolved and changed, based on evaluations and feedback received from the patients and their carers. In addition, ACT was not fully implemented from the very beginning. In that way ACT got a target group-specific application (Verhaegh, 2008a). This implies an underestimation of the effects found. On the other hand, the CAU group was not fully sized from the beginning; in that early period the professionals had more time to spend with their patients which, in total, neutralizes the former effect.
In both groups, many outcomes showed large improvements over the 2-year period.

Between-group differences were not always significant. This could be caused by a lack of power due to the relatively small numbers of patients in the groups.

To interpret the findings of this study correctly, we measured the level of fidelity of the CAU as offered to the control group in the present study. We completed the DACTS as an alternative, because the common procedure would be too time-consuming due to clients of the CAU group being spread over the three locations and because the present circumstances were relatively stable over time.

In contrast to the usual procedure, for the organizational items we interviewed the local manager, and for the items concerning the content of the program we interviewed a professional that was most familiar with the target group. In all cases we used the DACTS Score Sheet as a guideline. During the interviews it became clear that the information from the manager and the professional overlap. This was used to check whether the given data were indeed reliable. A third data source that gave specific insight in CAU was the patient files. These were examined twice for all patients in the CAU group.

Conclusions

Based on the outcomes investigated, this study shows that ACT and early psychosis yield an effective match. Compared with CAU, most of the outcome measures in ACT show a significantly better result, as well as better treatment results (greater improvements), over the 2-year study period.

References

- Archie, S., (2006). Integrated care improves one-year outcomes in first-episode psychosis. *Evidence-Based Mental Health*, 9 (2):46.
- Billings, J., Johnson, S., Bebbington, P., Greaves, A., Priebe, S., Muijen, M., et al.(2003). Assertive outreach teams in London: staff experiences and perceptions: Pan-London Assertive Outreach Study, Part 2. *Br J Psychiatry*, 183, 139-147.
- Drake, R., Goldman, H., Leff, H., Lehman, A., Dixon, L., Mueser, K., et al. (2001). Implementing Evidence-Based Practices in Routine Mental Health Service Settings. *Psychiatric Serv*, 52, 179-182.
- Burns,T., White, I., Byford, S., Fiander, M., Creed, F., Fahy, T. (2002). Exposure to case management: relationships to patient characteristics and outcome: Report from the UK700 trial. *Br J Psychiatry*, 181, 236-241.
- Byford, S., Fiander, M., Torgerson, D., Barber, J., Thompson, G., Burns,T., et al. (2000). Cost-effectiveness of intensive v. standard case management for severe psychotic illness: UK700 case management trial. *Br J Psychiatry*, 176, 537-543.
- Clark R.E., Teague, G.B., Ricketts, S.K., et al.(1998). Cost-effectiveness of assertive community treatment versus standard case management for persons with co-occurring severe mental illness and substance use disorders. *Health Services Research*, 33:1283-1306
- Cuddeback, G.S., Morrissey J.P., Meyer, P.S. (2006). How Many Assertive Community Treatment Teams Do We Need? *Psychiatr Serv* 57 (12):1803-1806.
- Davison, G. (2000). Stepped Care: Doing More With Less? *J Consult Clin Psychol*, 68(4) 580-585.
- Dixon, L. (2000). Assertive Community Treatment: Twenty-Five Years of Gold. *Psychiatric Serv*, 51, 759-765.
- Drake, R., Goldman, H., Leff, H., Lehman, A., Dixon, L., Mueser, K., Torrey, W., William, C. (2001). Implementing Evidence-Based Practices in Routine Mental Health Service Settings. *Psychiatric Serv*, 52, 179-182.
- Fenwick, E.P., & Byford, S.M. (Red). (2005). A guide to cost-effectiveness acceptability curves. *Br J Psychiatry*, 187, 106-108.
- Gaag, van der, M., Valmaggia, L.R., Meer, van, C.R., & Slooff, C.J. (2005). Gedachten uitpluizen: Handboek Theorie. *Cognitieve gedragstherapie bij achterdocht en stemmen*. Oegstgeest: Stichting Cognitie en Psychose, www.gedachtenuitpluizen.nl.
- Jeppesen, P., Petersen, L., Thorup, A., Abel, M.B., Øhlenschlæger, J., Christensen, T., Krarup, G., Hemmingsen, R., Jorgenson, P., Nordentoft, M. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden: OPUS trial. *Br J Psychiatry, 187 Suppl.* 48, s85-s90.
- Jørgensen, P., Nordentoft, M., Abel, M.B., Gouliaev, G., Jeppesen, P., Kassow, P. (2000). Early detection and assertive community treatment of young psychotics: the Opus Study. Soc *Psychiatry Psychiatr Epidemiol*, V35 (7):283-287.

- Latimer, E. (1999). Economic impacts of ACT: a review of the literature. Review of Reviewed Item. *Can J Psychiatry,* (5).
- Lehman, A.F., Dixon, L., Hoch, J.S., Deforge, B., Kernan, E., Frank, R. (1999). Cost-effectiveness of assertive community treatment for homeless persons with severe mental illness. *Br J Psychiatry,* 174 (4):346-352.
- Killaspy, H., Bebbington, P., Blizard, R., Johnson, S., Nolan, F., Pilling, S., King, M. 2006. The REACT study: randomised evaluation of assertive community treatment in north London. BMJ, 332, 815-820.
- Kuipers, E., Holloway, F., Rabe-Hesketh, S., Tennakoon, L. (2004). An RCT of early intervention in psychosis: Croydon Outreach and Assertive Support Team (COAST). *Soc Psychiatr Psychiatric Epidemiol,* 39 (5) 358-363.
- Marshall, M., & Lockwood, A. (1998). Assertive Community Treatment for those with severe mental disorders, *Cochrane Library,* vol. 5, no. 2.
- McGlashan, T.H. (2005). Early detection and intervention in psychosis: an ethical paradigm shift. *Br J Psychiatry*, 187, 113-115.
- McGorry, P.D., Pelosi, A.J. (2004). Value of early intervention in psychosis. *Br J Psychiatry*, 185, 172.
- McGorry, P., Nordentoft, M., Simonsen, E. (2005). Introduction to 'Early psychosis: a bridge to the future'. *Br J Psychiatry,* 187, 1-3.
- McGorry, P.,Killackey, E., & Yung, A. (2007). Early intervention in psychotic disorders: detection and treatment of the first episode and the critical early stages. *Med J Australia,* 187 (7 Suppl): S8-S10.
- Mueser, K., Bond, G., Drake, R., & Resnick, S. (1998). Models of community care for severe mental illness: a review of research on case management. *Schizophrenia Bulletin*, vol. 24, no. 1, pp. 37-74.
- Nordentoft, M.,Thorup, A., Petersen, L., Øhlenschlæger, J., Christensen,T., Krarup, G., et al. (2008). Does a detection team shorten duration of untreated psychosis? *Early Intervent Psychiatry,* 2: 22–26.
- Nordentoft, M., Jeppesen, P., Petersen, L. (2003). OPUS project: a randomised controlled trial of integrated psychiatric treatment in first-episode psychosis. *Schizophrenia Res,* 60, 297.
- Nolen (2008). Clinical Global Impression Scale, www.tijdschriftvoorpsychiatrie.nl/meetinstrumenten/download.php?id=29.
- Norman, R., Lewis, S., Marshall, M. (2005). Duration of untreated psychosis and its relationship to clinical outcome. *Br J Psychiatry,* 187, s19-s23.
- Pelosi, A.J., Birchwood, M. (2003). Is early intervention for psychosis a waste of valuable resources? *Br J Psychiatry,* 182 (3):196-198.
- Perkins, D., Gu, H., Boteva, K., Lieberman, J. (2005). Relationship between duration of untreated psychosis and outcome in first-episode schizophrenia: A Critical Review and Meta-Analysis. [Miscellaneous Article]. *Am J Psychiatry*, 162, 1785-1804.

- Petersen, L., Jeppesen, P., Thorup, A., Abel, M.B., Øhlenschlæger, J., Christensen, T.Ø., Krarup, G., Jorgensen, P., Nordentoft, M. (2005) A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *BMJ*, 331: 602-5.
- Priebe, S., Fakhoury, W., White, I., Watts, J., Bebbington, P., Billings, J., et al. (2004). Characteristics of teams, staff and patients: associations with outcomes of patients in assertive outreach. *Br J Psychiatry*, 185, 306-311.
- Rosenheck, R., Neale, M.S. (2001). A Critique of the Effectiveness of Assertive Community Treatment. *Psychiatr* Serv, 52 (10):1395-1396.
- Singh, S P., Fisher, H.L. (2005). Early intervention in psychosis: obstacles and opportunities. *Adv Psychiatr Treat*, 11 (1):71-78.
- Teague, G.B., Bond, G.R., Drake, R.E. (1998). Program fidelity in assertive community treatment: development and use of a measure. *Am J Orthopsychiatry*, 68, 216-232.
- Test, M., Stein, L. (2001). A Critique of the Effectiveness of Assertive Community Treatment. *Psychiatric Serv*, 52, 1396-1397.
- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. (2008a). Model fidelity of Assertive Community Treatment for clients with first-episode psychosis: a targetgroup-specific application. *Community Mental Health J*, 45(1):12-18.
- Verhaegh, M.J.M., Dietvorst, I.A.R., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. Cost-effectiveness of Assertive Community Treatment versus Care as Usual for young persons suffering from first-episode psychosis (2008b, in press).
- Weaver, T., Tyrer, P., Ritchie, J., Renton, A. (2003). Assessing the value of assertive outreach: Qualitative study of process and outcome generation in the UK700 trial. *Br J Psychiatry*, 183, 437-445.
- Yang, J., Law, S., Chow, W., Andermann, L., Steinberg, R., Sadavoy, J. (2005). Best Practices: Assertive Community Treatment for persons with severe and persistent mental illness in ethnic minority groups. *Psychiatr Serv*, 56 (9):1053-1055.
- Wunderink, A. (2006). Antipsychotic treatment strategies and early course of first episode psychosis. Dissertation, Rijks Universiteit Groningen, Groningen.

CHAPTER 6

ASSERTIVE COMMUNITY TREATMENT AND EARLY PSYCHOSIS RECOVERY OUTCOME AFTER A TWO-YEAR TREATMENT PERIOD

Abstract

Objective

Assertive Community Treatment (ACT) is described as a team treatment model designed to provide assertive, outreaching, comprehensive, community-based, rehabilitation-oriented and supportive psychiatric services for people with severe mental illness. Studies have shown promising outcome results when applying ACT to young patients suffering from a first-episode psychosis. The present study followed a group of young patients for a two-year period to establish their recovery process in relation to ACT.

Methods

A Dutch mental healthcare institution (Mental Healthcare Eindhoven) provided fully implemented ACT and established the impact of ACT on the recovery of patients. Three outcome areas (and their related instruments) were defined: quality of life (WHO QoL-BREF, Empowerment), Psychosocial (Demand-oriented Care list, Involvement Evaluation Questionnaire), and Psychopathology (GAF, CGI, HoNOS and PANSS). Data for these areas were obtained at baseline and after 1 and 2 years follow-up and collected from patient files, questionnaires and interviews.

Results and conclusions

This study shows that ACT contributes to a successful recovery process of young people suffering from psychosis. Patients improved quickly with regard to psychopathology, gain and regain of social roles, and showed improvement on quality of life and empowerment. Carers play an important role in supporting these patients and are key figures in the social (safety) network.

Introduction

Assertive Community Treatment (ACT) is a well-known evidence-based practice that is frequently applied because of its positive impact on, in particular, the target group of severely mentally ill persons (Marshall, & Lockwood, 1998; Drake, et al., 2001; Dixon, 2000; Teague, Bond, & Drake, 1998; Mueser, Bond, Drake, & Resnick,1998). In several countries ACT has proven to be an effective and efficient treatment model for the group of patients mostly described as "Severe Mentally Ill" (SMI). The model was designed in the United States in the 1970s by Stein and Test. From the beginning they intended to create a model that offers SMI patients an alternative to hospitalization; the target group left the hospital and learned how to live in the community. Typical features of this model are: the attitude of the professionals is proactive and assertive, treatment takes place in the community, a multi-disciplinary team is responsible for a group of patients, and the team delivers all the services required.

ACT for patients with early psychoses

Based on studies on the Duration of Untreated Psychosis (DUP) and on treatment during the critical period (the first 3-5 years after the appearance of the first positive symptoms) (McGlashan, 2005; McGorry, Nordentoft, & Simonsen, 2005), in Mental Healthcare Eindhoven the ACT team chose to treat every patient with ACT for 3 years before transferring them (when indicated) to appropriate subsequent treatment.

Events in the critical period determine the future course of the recovery process and functioning of the patient (Spencer, Birchwood, & McGovern, 2001; McGlashan, 1999; Scully, Coakley, Kinsella, & Waddington, 1997). A positive correlation has been shown between improved outcome of treatment and a shorter DUP (McGlashan, 2005; McGorry, et al., 2005; McGorry, & Pelosi, 2004; Norman, Lewis, & Marshall, 2005; Perkins, Gu, Boteva, & Lieberman, 2005). The intensive outreach and assertive features of ACT are important in this context.

In various countries ACT is increasingly and successfully applied to patients with a first-episode psychosis (Jeppesen, Petersen, Thorup, Abel, & Øhlenschlæger, 2005; Nordentoft, Jeppesen, & Petersen, 2003). In the Netherlands, however, outcome studies and published reports are scarce.

In the present study outcome is defined as the extent to which a patient recovers from his/her psychosis. Recovery is defined as: *"...a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"* (Anthony, 2000).

This study addresses the following research question: What effect does ACT (provided in and around the city of Eindhoven) have on the recovery outcome of patients who suffer from a first-episode psychosis over a 2-year treatment period?

Methods

In July 2004 a mental healthcare organisation in the southern part of the Netherlands (Mental Healthcare Eindhoven) started to treat a group of patients according to the principles of ACT (Verhaegh, 2008a). The study protocol was submitted for approval to an accredited Medical Ethics committee in November 2004; approval was subsequently received.

The target group consists of all patients with a first psychotic episode (excluding substance-induced psychotic disorders) generally in the age group 18 to 35 years. The catchment area includes about 500,000 inhabitants, of whom 210,000 live in Eindhoven city centre.

Target group and inclusion process

Every newly included patient in ACT was asked to participate in the study. After 2 years, of the 105 patients included in ACT, 62 (59%) signed informed consent and were included in the present study

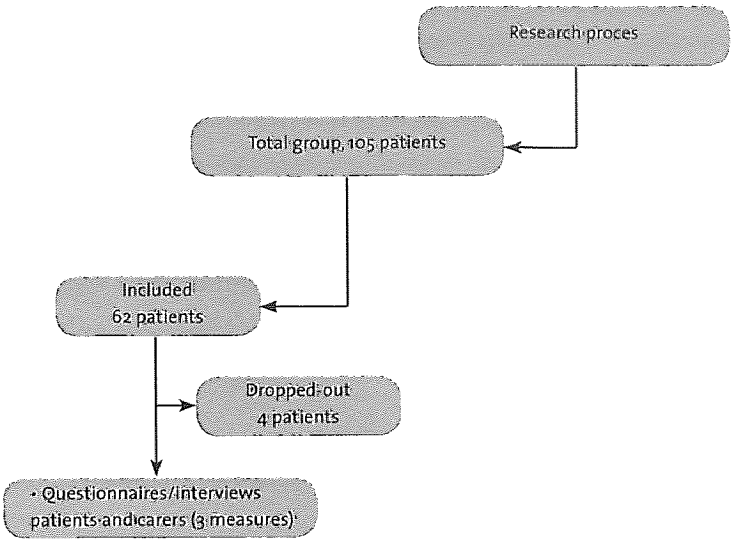
Of these 62 patients, 51 completed all 3 measurements; 7 completed 2 measurements, and 4 patients completed one measurement (Figure 1). These latter 4 patients were excluded from the analyses.

Criteria for inclusion in ACT were:

- the patient suffers from a first-episode psychosis;
- the patient recently (during the previous year) had the first positive symptoms;
- the patient has psychotic disorder(s), including schizophrenia and all sub-types;
- the patient has sufficient command of the Dutch language;
- the patient signs an informed consent (for use of data from the questionnaires).

Patients suffering from organic psychiatric disorders, and patients with mental retardation co-morbidity (IQ <80) were excluded from the study.

Figure 1. Flow chart showing the study process.



Data collection

Data were assessed at baseline (usually 1-3 months after the first-episode of psychosis), and at 1 and 2-year follow-up. Data regarding the patients' experiences of ACT/quality of life (QoL) were collected either by client interviewers or by researchers (Verhaegh, 2008b). Data on the psychosocial and psychopathology areas were obtained by the researchers and team members.

Inter-rater reliability was controlled by group training for team members (HoNOS and PANSS), and for client researchers and researchers (QoL, Empowerment). In those training sessions, the inter-rater reliability proved to be good. During the 2-year study period, meetings were planned to discuss and deal with potential differences in rating and interpreting cases; no important deviations in inter-rater reliability occurred.

Three areas were chosen to cover the definition of 'recovery', with the outcome domains: Quality of life, Psychosocial, and Psychopathology. For each outcome area representative measurement instruments were selected.

Quality of life area

Two measurement instruments were used to determine the effects experienced by patients: the brief version of the WHO Quality of Life scale (WHO QOL-BREF) (Vries de, and Heck van, 1996), and the Empowerment Scale (Rogers, et al., 1997).

The WHO QOL-BREF comprises 26 items which measure (on a 5-point Likert scale) the following 4 domains (24 items): physical health, psychological health, social relationships, and

environment, as well as a summarizing overall score (2 items). The Dutch version was used in all cases, except for one patient who preferred the English version. The psychometric features of the WHO QOL-BREF are reported to be good (Trompenaars, et al., 2005).

The Empowerment scale (Rogers, et al., 1997) comprises 6 subscales: Self Esteem/Self-Efficacy, Power/Powerlessness, Community Activism and Autonomy, Optimism and Control over the Future, Righteous Anger, and Overall Empowerment. The Empowerment scale has shown adequate validity in a population of outpatient mental health patients (Wowra, 1998; Scott, et al., 1999).

Psychosocial area

For this area data were collected data using the subscale 'Living, working and leisure' from the Demand-oriented Care list. This list and subscales have shown sufficient validity (Weert-van Oene de, et al., 2006).

For family burden we used the Involvement Evaluation Questionnaire (Wijngaarden van, et al., 1997 and 2000) which consists of 1 overall score for 27 items that are divided in 4 subscales: Tension (the strained interpersonal atmosphere between patient and relatives), Supervision (the caregiver's tasks of guarding the patient's medicine intake, sleep and dangerous behaviour), Worrying (covers painful interpersonal cognitions), Urging (refers to activation and motivation), and a Remainder group.

In addition, for this area we collected data from medical files concerning living, and the school/work situation to get an impression of the social circumstances of the patients.

Psychopathology area

The clinical effects of ACT were examined using 4 instruments:

- the Positive and Negative Syndrome Scale (PANSS) measures positive/negative symptoms and general psychopathology on 3 subscales (Kay, 1987).
- the Health of Nation Outcome Scale (HoNOS) considers different aspects of mental and social health, each scored on a 4-point scale. The scale consists of 4 subscales (behaviour, impairments, social, and symptoms) and has been shown to have sufficient validity and reliability (Mulder, 2004; Wing, 1996).
- the Clinical Global Impression scale (CGI) is designed to assess the global severity of illness and change in the clinical condition over time. The scale consists of 3 global subscales: Severity of illness, Global improvement, and Efficacy index. The Dutch version used in the present study consists of the first two subscales only (Nolen, 2008)

- the Global Assessment of Functioning (GAF) is a single-item rating scale for clinicians to rate the overall psycho-social functioning of patients; it has 10 anchor points and continuous scores ranging from 1-100 (Endicott, et al., 1976).

For this psycho-pathology area we also collected data from the medical files on the number of hospital admissions, the number of (tentative) suicide attempts, substance abuse, and compliance with treatment and medication (=cooperative with treatment plan, appointments and medication).

ACT and provided services

Within the specific ACT organizational context, the ACT team aims to provide essential services: whenever possible evidence-based but, if not available, then based on best practices and professional experiences. A prominent starting point is the recovery process of the patient. All team members are experienced and trained (Boston Psychiatric Rehabilitation) employees that meet the needs of the patients and carers, and contribute to their recovery process using specific communication techniques and rehabilitation-based services and interventions (readiness assessment, Liberman modules). Distinctive values are: easily accessible services and staff, and that communication is on an equal basis between team members, as well as between professionals and patients/carers.

ACT offers a multidisciplinary team approach and provides integrated intensive care (treatment, plus support geared to patients with co-morbid disorders) in a pro-active way. There is a low case load (staff/patient ratio of 1:10 or less). The ACT team provides most of the services directed at all dimensions of daily life. Most services are provided within the community.
Outside of normal working hours, the ACT team is supplemented by a crisis intervention service (including a shared electronic patient file system and crisis intervention plan); during the weekend one of the ACT staff can be reached by phone. The entire ACT team has daily briefings (Verhaegh, 2008a).

Services

Case management focuses on social functioning and role fulfilling, observing (side) effects of medication, compliance with medication, intervening in family and carer systems, and providing crisis intervention techniques, psycho-education and medication.
Cognitive Behavioural Therapy (CBT) aims to replace or transcend the inadequate thoughts or behaviours with more realistic and useful ones. A specific, frequently applied variant is CBT for psychosis, i.e. the unravelling of thoughts and ideas (in Dutch: 'gedachten uitpluizen') (Gaag, 2005).

Psycho-education in family and patient groups aims to increase patients' and carers' knowledge and understanding of illness and treatment. It is assumed that increased knowledge will enable persons with psychosis to cope more effectively with their illness. It is provided separately for carers and patients in order to pay maximum attention to specific demands and issues.

The ACT provides treatment elements of an *integrated Double-Diagnosis treatment* model. This means an integrated treatment for both autonomous, but interacting disorders (psychiatric disorder and substance abuse).

Vocational training and school support intends to support patients in choosing, gaining and maintaining a job, education or day activities starting from an evidence-based practice (Individual Placement and Support, and Supported education techniques).

The ACT *Housing support* professional focuses on providing patients with a place to live of their own choice. He operates in social networks and negotiates with housing companies, parents and patients to find the best-fitting solution to the housing demand of the patient. This is important because homelessness often leads to hospitalization. All kinds of tasks related to housing are dealt with by the housing specialist, e.g. financial, hygiene, nutritional, and furniture issues.

The peer group worker *(Individual and group peer support)* is a professional, fully responsible and informed member of the team. He operates from own experiences combined with techniques on how to apply the experiences in an optimal balance between maximum involvement on the one hand, and a professional distance on the other. The peer group worker provides a low level access and focuses on all kinds of thoughts, anxieties, and uncertainties related to the patient's disorders.

Pharmacotherapy is a key element in ACT treatment. The psychiatrist always first connects to the patient (and their carers) and starts from the present medication policy and professional guidelines. Except for emergency situations, pharmacotherapy is primarily based on an intention to consensus.

Statistical analyses

Analyses were performed using SPSS 14.0. The one-way repeated measures test was used to explore differences in improvement over the 2-year period.

The dependent sample T-test was used to explore differences between the groups over the 2-year period when only 2 measurements were available.

The level of significance in all tests was set at a p-value <0.05.

Results

Target group

Table 1 presents the characteristics of the target group. Compared with the non-response group, study patients showed no differences on examined characteristics (age, gender, and DSM-IV diagnosis), but scored significantly better on the GAF (p=0.004) and the CGI scales (p=0.001) indicating that they were in better condition from a psychopathological point of view.

Table 1. Characteristics of the target group

Sample/group size	Baseline (N=62)
Age	
Mean (SD)	26 (SD=3.5)
Male (SD)	24.8 (SD=5.7)
Female (SD)	30.1 (SD=2.8)
Range	17–56
Gender %	
Male	78%
Female	22%
Marital status %	
Single	83%
Married/cohabitant	14%
Separated/divorced	1.5%
Widow	1.5%
Highest level of education	
Primary school	8.6%
Secondary school	43.1%
Professional education	29.3%
University/High school	11%
Bachelor	7.5%
Master (+)	3.5%
Psychopathologic functioning	
GAF score (SD)	43.39 (SD=12.2)
CGI score (SD	4.31 (SD=1.12)
DSM-IV	
Psychosis NOS	45%
Schizophrenia, subtypes	29%
Rest group	26%

During the 2-year treatment period none of the 62 patients dropped-out; however, data from 4 patients could not be used because only one measurement was made. Three patients were involved in criminal activities and were referred to jail or forensic treatment services; 1 of these continued in the study and completed a second measurement. Two patients stated that they were no longer motivated to participate (probably due to the negative symptoms of their illness). Therefore, when excluding these patients, the target group comprises 58 persons.

Quality of life area

Table 2 shows the patients' judgements on the Quality of Life (QoI) scale and the Empowerment scale. During the 2-year treatment period the overall QoL on 24 items increased significantly ($p<0.0005$); the summarizing QoL score also increased ($p<0.0005$). All 4 of the QoL domains showed a significant improvement: Physical health ($p=0.01$), Psychological health ($p<0.0005$), Social relationships ($p=0.004$) and Environmental ($p=0.007$).

Table 2. Scores on Quality of life area and measures

	T0 (n=55)[1]		T1 (n=55)		T2 (n=55)[1]		GLM repeated measures
Scale/Subscales	Mean	SD	Mean	SD	Mean	SD	ANOVA ($P<0.05$)
WHO QOL- Bref							
Physical health	23.34	(5.6)	24.38	(5.5)	25.36	(5.5)	F=4.98, p=0.010
Psychological health	18.76	(3.4)	19,81	(3.8)	21.00	(4.4)	F=14.58, p<0.0005
Social relationships	9.91	(2.0)	10.17	(2.4)	10.78	(2.7)	F=6.20, p=0.004
Environmental	28.48	(4.8)	29.21	(4.6)	30.36	(4.8)	F=5.53, p=0.006
Overall QOL	**79.76**	**(12.6)**	**82.85**	**(13.6)**	**86.98**	**(14.7)**	**F=10.14, p<0.0005**
Summarizing score	**6.47**	**(1.5)**	**7.07**	**(1.5)**	**7.59**	**(1.7)**	**F=14.61, p<0.0005**

Empowerment	T0 (n=58)		T1 (n=58)		T2 (n=58)		
Self-esteem/ Self-efficacy	24.69	(3.7)	26.03	(4.0)	28.05	(4.0)	F=29.01, p<0.0005
Power/Powerlessness	15.21	(2.3)	16.28	(2.3)	17.29	(2.5)	F=25.58, p<0.0005
Community Activism and Autonomy	18.17	(1.7)	18.78	(2.0)	19.72	(2.3)	F=27.27, p<0.0005
Optimism and control over future	7.97	(1.4)	8.24	(1.6)	8.81	(1.4)	F=11.72, p<0.0005
Righteous anger	9.78	(1.9)	10.17	(1.9)	10.91	(2.0)	F=13.58, p<0.0005
Overall Empowerment	**75.81**	**(6.3)**	**79.50**	**(7.3)**	**84.79**	**(8.0)**	**F=45.21, p<0.0005**

Table 2 shows that the overall Empowerment scores had a (linear-type) significant increase over the 2 years ($p<0.0005$). The improvements in the 5 Empowerment sub-scales were also significant: Self-esteem/Self-efficacy ($p<0.0005$), Power/Powerlessness ($p<0.0005$), Community Activity and Autonomy ($p<0.0005$), Optimism and control over the future ($p<0.0005$) and Righteous anger ($p<0.0005$).

Psychosocial area

At baseline, 39% of all patients lived with their parents compared with 33% after 2 years, 11% lived with a partner (and children) compared with 21% after 2 years, and 31% lived alone at baseline compared with 26% after 2 years. The remainder (19% at baseline and 20% after 2 years) did not have a stable living situation (temporary rooms, living with friends, or hospitalized).

For daily activities, at baseline 39.2% worked or attended school compared with 50.1% after 2 years, and 32% had social activities compared with 21% after 2 years. Of the remainder, 28.8% at baseline and 28.9% after 2 years had activities within their own family (e.g. educating their children, housekeeping) or were too ill to be active.

Carers and patients have frequent contact. In 79% of all cases the carers support their son or daughter; 21% has no contact due to illness-related reasons (6%), living abroad (11%), or unknown reasons (3%). At baseline the carers spent (on average) 4.29 hours per week supporting their child; after 2 years this had decreased to (on average) 4.09 hours per week. Activities performed by carers include: controlling medication, regulating the structure of daily life, encouraging social activities, and guarding against dangerous acts, self-inflicted harm, and substance abuse.

From the Involvement Evaluation Questionnaire (IEQ) we obtained data from 1 overall score and 4 subscales (Tension, Supervision, Worrying, Urging), as well as from a 'Remainder' group covering the carer's personal circumstances (Table 3).

The overall score on the IEQ decreased during the 2 years, indicating that carers became less involved and that the carers' burden decreased over the treatment period. This improvement was significant ($p<0.0005$).

Table 3. Scores on the Involvement Evaluation Questionnaire

	T0 (n=51)		T1 (n=51)		T2 (n=51)		GLM repeated measures ANOVA (P<0.05)
Scale/Subscales	Mean	SD	Mean	SD	Mean	SD	
IEQ							
Tension	14.39	4.3	13.71	4.3	13.18	3.9	F=6.88, p=0.002
Supervising	8.65	3.1	7.65	2.7	7.59	2.6	F=9.84, p<0.0005
Worrying	14.67	5.5	13.16	5.8	13.04	5.7	F=4.56, p=0.015
Urging	19.50	6.0	15.10	6.5	14.04	5.5	F=21.63, p<0.0005
Remainder	12.02	2.9	11.16	3.0	10.94	2.8	F=1.45, p=0.245
Overall Score	**57.28**	**14.1**	**49.46**	**16.0**	**47.74**	**14.5**	**F=16.85, p<0.0005**

The Tension sub-scale shows a significant improvement over 2 years (p=0.002), as does the Supervising sub-scale (p<0.0005). The scores on the Worrying sub-scales and the Urging sub-scale also showed significant improvements: p=0.015 and p<0.0005, respectively.

The Remainder group is not a sub-scale but provides additional information on the following: the carer pursuing their own activities and interests, getting the carer accustomed to one's relative/friend's mental problems, coping with the relative/friend's mental health problems, and changes in the quality of the relationship with relative/friend. In this category there were no significant improvements over time (p=0.245).

Psychopathology area

The scores on the PANSS (Table 4) show improvements on the total score as well as on all 3 sub-scales. Patients scored significantly better on Positive and Negative symptoms and General psychopathology over the 2-year period; all p-values were ffi0.005. In this area the overall improvement over time was significant (p<0.0005).

The total score on the Health of Nation Outcome Scale improved (i.e. the score decreased) after 2 years (p<0.0005) (Table 4).

Table 4. Scores on the psychopathology area; PANSS and HoNOS

	To (n=54)		T1 (n=54)		T2 (n=54)		GLM repeated measures ANOVA (P<0.05)
Scale / Subscales	Mean	SD	Mean	SD	Mean	SD	
PANSS							
Positive symptoms	13.33	(6.1)	11.56	(4.8)	10.17	(3.7)	F=9.99, p<0.0005
Negative Symptoms	15.06	(5.5)	12.46	(4.4)	11.41	(3.8)	F=10.87, p<0.0005
General psychopathology	30.94	(10.0)	25.80	(6.9)	23.89	(6.2)	F=14.18, p<0.0005
Total score	**60.46**	**(19.6)**	**49.87**	**(13.8)**	**45.50**	**(12.1)**	**F=16.85, p<0.0005**
HONOS	(N=58)		(N=58)		(N=58)		
Social functioning,	4.26	(2.8)	3.52	(2.4)	3.34	(2.4)	F=3.73, p<0.0005
Impairments	2.21	(1.4)	1.62	(1.3)	1.67	(1.4)	F=4.12, p=0.021
Symptoms	4.74	(2.3)	3.47	(2.2)	2.78	(2.1)	F=17.62, p<0.0005
Psychiatric behaviour	1.95	(2.2)	1.66	(1.9)	1.41	(1.9)	F=2.31, p=0,109
Total score	**13.28**	**(6.6)**	**10.09**	**(5.5)**	**8.84**	**(5.0)**	**F=22.94, p<0.0005**

The sub-scales Social functioning, Impairments and Symptoms also showed significant improvements over 2 years (Social functioning: p=0.03, Impairments: p=0.021, Symptoms: p<0.0005). However, the subscale Psychiatric behaviour showed no significant improvement (p=0.109). The four most frequently occurring problems on this sub-scale were: anxiety (28% at baseline), mental strain (15% at baseline), obsessive/compulsive problems (12% at baseline), and sleeping problems (10% at baseline). The percentages on these sub-scales showed no or very small improvements over the 2 years. The percentage of patients that mentioned mental strain increased from 15% at baseline to 19% at the end of treatment.

Table 5. Scores on the psychopathology area; GAF and CGI

	baseline	1 year	2 years	One-way repeated measures ANOVA
GAF (n=58)	43.71 (SD 12.0)	47.93 (SD 15.1)	53.19 (SD 15.9)	F = 17.21, p<0.0005
CGI (n=58	4.26 (1.1)	3.38 (1.3)	2.78 (1.3)	F = 48.37, p<0.0005

(Sign. level p<0.05)

Over the 2-year study period the GAF score of both groups improved significantly (Table 5). The mean score increased from 43.71 at baseline to 47.93 after 1 year and to 53.19 after 2 years (p<0.0005). The score on the CGI improved (i.e. the score decreased) over 2 years from 4.26 at baseline to 3.38 after 1 year and to 2.78 after 2 years (p<0.0005).

Medical file information

In-patient days and crises

Over a 2-year period in the ACT group the average number of in-patient days per patient was 27 days; the hospital admission rate due to crises was 0.44 per patient over 2 years. In a similar group of patients provided with care as usual (Chapter 5), the average number of inpatient days during the 2-year study period was 70 per client, and the hospital admission rate due to crises was 0.95 per patient over 2 years. In both situations the differences were significant (T-test, p=0.021 and p=0.012, respectively).

Substance abuse

Of the 58 patients at baseline, 27% abused drugs and 12% abused alcohol; after 2 years these percentages were 25% for drugs and 12% for alcohol (T-test for drugs p=0.71; for alcohol p=0.38).

Suicidal behaviour

Over the 2-year period no patient committed suicide but 2 patients attempted suicide (one time each). Suicidal behaviour occurs regularly but generally does not lead to serious or dangerous actions.

Compliance

Treatment compliance improved significantly over the 2-year period. Patients had a mean baseline score of 1.47 and a score of 1.29 after 2 years; this improvement was significant (T-test, 2-sided, p=0.032). Compliance with medication showed no improvement: at baseline the score was 1.47 compared with 1.62 after 2 years (T-test, 2-sided, p=0.252).

Discussion and conclusions

Discussion

This study explored whether ACT services contribute to the recovery of young patients suffering from early psychosis. To address this question we chose three areas of interest: Quality of life, Psychosocial, and Psychopathology. We found substantial improvements over the 2-year treatment period in nearly every aspect under study.

Quality of life area

There were highly relevant improvements on the Quality of Life scale and on the Empowerment scale indicating that after psychotic crises most patients are able to continue with their lives and, very soon after the start of ACT, experience better quality of life and empowerment. The greatest part of the total improvement is achieved within the first year.

Psychosocial area

Particularly for patients in this stage of development, the social environment (parents, family, friends, partner) fulfils an important role. The members of the environment create a safety net, prevent the patient from getting worse, observe the mental condition, provide a social laboratory to practice new skills/insights, and provide general support (Mueser, & Gingerich, 2006). In this important role, however, the carers often feel burdened (Ostman, Wallsten, & Kjellin, 2005; McFarlane, Dixon, Lukens, & Lucksted, 2003; Perlick, Rosenheck, Kaczynski, Swartz, et al., 2006). ACT interventions (family group psycho-education, individual support, and regular discussion meetings) aim to reduce the 'burden' of family/carers.

Most patients have functional network contacts, generally with their parents. The Involvement Evaluation Questionnaire yielded information about the intensity and sort of contacts the carers have with their children, and how intrusive it is on their lives. This study reveals that the quantity of contacts with their children does not change over time but the impact of the burden is significantly reduced.

Because carers fulfil a very important social safety network it is recommended to explore in more detail how to improve the outcome concerning the carers' issues. We suggest that involving the carers in ACT should be part of the overall treatment concept.

Psychopathology

All measurements concerning psychopathology show significant improvements. Scores on the GAF, CGI, PANSS and HoNOS improved over time and show the most gain in the first year of treatment.

The only exception was the sub-scale Psychiatric behaviour of the HoNOS; this showed no significant improvement after 2 years. The main problems on this sub-scale were: anxiety (28% at baseline), mental strain (15% at baseline), obsessive/compulsive problems (12% at baseline), and sleeping problems (10% at baseline).

Regarding inpatient days, after their initial psychotic crisis most of the patients experience no relapses that lead to admissions.

We found no improvement on drug and alcohol abuse in this study, despite the presence of treatment elements of an Integral Double Diagnosis treatment model. However the model was not implement the entirely according to the IDD-fidelity scale. This could be a reason of the disappointing result of Double Diagnosis treatment in ACT. the reasons for this also need further investigation.

Treatment compliance was significantly better after 2 years treatment. The ACT team pays much attention to the alliance between patients and carers; a good relationship between professionals and patient/carers is considered a necessary condition for successful treatment.

Compliance with medication is less successful, perhaps due to the priority given to a good alliance with the patients.

Suicidal behaviour is an important issue; patients in crisis think about the meaning of life and try to find solutions for their problems. ACT professionals address these issues and found a balance between the risk for suicidal behaviour and unnecessary interventions.

Limitations to this study

One limitation of the present study is that we cannot compare the results with those of a control group. However, in a quasi-experimental comparison with CAU in a neighbouring region, ACT showed (significant) better outcome results on number and duration of admissions, work/school rates, social adjustment, alcohol usage, suicidal behaviour, and treatment compliance (Verhaegh, 2008c, in press).

All patients who received ACT treatment (n=105) were asked to participate in this study; the final target group consisted of the 62 patients who agreed to participate. A non-response analysis showed better scores on the GAF and CGI scales in the target group, indicating that they were in a better psychopathological condition. The other characteristics showed no differences (age, gender, and DSM-IV diagnosis). This implies that the present results should be interpreted with caution and may present some overestimation of the 'real' situation.

Conclusions and recommendations

The group of patients in the present study recovered soon after ACT treatment started. When the most severe psychopathology has disappeared (after the first few weeks/month of the illness) social recovery must start immediately. Services should be focused on issues concerning 'normal life', i.e. gaining and regaining social roles and responsibilities. An important item to be addressed is the involvement of carers in the treatment of patients, and helping these carers to avoid the related 'burden' of such involvement.

Because recovery is a multi-dimensional (not sequential) process, ACT is suitable as a treatment model. ACT is outreaching, pro-active and multi-disciplinary and makes a successful contribution to the (re-)integration of patients in their own network.

References

- Anthony, W. (2000). A Recovery-Oriented Service System: Setting Some System Level Standards. *Psychiatr Rehabil J*, 24(2), 159-168.
- Burns,T., White, I., Byford, S., Fiander, M., Creed, F., Fahy, T. (2002). Exposure to case management: relationships to patient characteristics and outcome: Report from the UK700 trial. *Br J Psychiatry*, 181, 236-241.
- Dixon, L. (2000). Assertive Community Treatment: Twenty-Five Years of Gold. *Psychiatric Serv*, 51, 759-765.
- Drake, R., Goldman, H., Leff, H., Lehman, A., Dixon, L., Mueser, K., Torrey, W., William, C. (2001). Implementing Evidence-Based Practices in Routine Mental Health Service Settings. *Psychiatric Serv*, 52, 179-182.
- Endicott, J., Spitzer, R.L., Fleiss, J.L., Cohen, J. (1976). The Global Assessment Scale: A procedure for measuring overall severity of psychiatric disturbance. *Arch Gen Psychiatry*, 33, 766-771.
- Gaag, van der, M., Valmaggia, L.R., Meer, van, C.R., & Slooff, C.J. (2005). *Gedachten uitpluizen: Handboek Theorie. Cognitieve gedragstherapie bij achterdocht en stemmen.* Oegstgeest: Stichting Cognitie en Psychose, www.gedachtenuitpluizen.nl.
- Jeppesen, P., Petersen, L., Thorup, A., Abel, M.B., Øhlenschlæger, J., Christensen, T., Krarup, G., Hemmingsen, R., Jorgenson, P., Nordentoft, M. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden: OPUS trial. *Br J Psychiatry*, 187 Suppl. 48, s85-s90.
- Kay, S.R., Fiszbein, A. & Opler, L.A. (1987). The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophrenia Bulletin*, 13, (2), 261-276.
- Marshall, M., & Lockwood, A. (1998). Assertive Community Treatment for those with severe mental disorders, *Cochrane Library*, vol. 5, no. 2.
- McFarlane, W.R., Dixon, L., Lukens, E., Lucksted, A. (2003) Family psychoeducation and schizophrenia: a review of the literature. *J Marital Fam Ther*, 29(2):223–245.
- McGlashan, T.H. (1999). Duration of untreated psychosis in first-episode schizophrenia: marker or determinant of course? *Biolog Psychiatry*, 46, 899-907.
- McGlashan, T.H. (2005). Early detection and intervention in psychosis: an ethical paradigm shift. *Br J Psychiatry*, 187, 113-115.
- McGorry, P.D., Pelosi, A.J. (2004). Value of early intervention in psychosis. *Br J Psychiatry*, 185, 172.
- McGorry, P., Nordentoft, M., & Simonsen, E. (2005). Introduction to 'Early psychosis: a bridge to the future'. *Br J Psychiatry*, 187, 1-3.
- Mueser, K.T., Gingerich, S. (2006). The Complete Family Guide to Schizophrenia. *The Guilford Press*. New York, London.
- Mueser, K., Bond, G., Drake, R., & Resnick, S. (1998). Models of community care for severe mental illness: a review of research on case management. *Schizophrenia Bulletin*, 24 (1), 37-74.

- Mulder, C.L., Staring, A.B.P., Loos, J., Buwalda, V.J.A., Kuijpers, D., Sytema, S., Wierdsma, A.I. (2004). De Health of the Nation Outcome Scales (HoNOS) als instrument voor 'routine outcome assessment', *Tijdschrift voor Psychiatrie*, 46, 5, 273-284.
- Nolen (2008). Clinical Global Impression Scale, www.tijdschriftvoorpsychiatrie.nl/meetinstrumenten/download.php?id=29.
- Nordentoft, M., Jeppesen, P., Petersen, L. (2003). OPUS project: a randomised controlled trial of integrated psychiatric treatment in first-episode psychosis. Schizophrenia Res, 60, 297.
- Norman, R., Lewis, S., Marshall, M. (2005). Duration of untreated psychosis and its relationship to clinical outcome. *Br J Psychiatry*, 187, s19-s23.
- Ostman, M., Wallsten, T., & Kjellin, L. (2005). Family Burden and Relatives' Participation in Psychiatric Care: Are the Patient's Diagnosis and the Relation to the Patient of Importance? *Int J Soc Psychiatry*, 51(4): 291-301.
- Perlick, D.A., Rosenheck, R.A., Kaczynski, R.M.D., Swartz, M.S., Cañive,J.M. and Lieberman, J.M. (2006). Components and Correlates of Family Burden in Schizophrenia. *Psychiatr Serv*, 57: 1117-1125.
- Perkins, D., Gu, H., Boteva, K., Lieberman, J. (2005). Relationship between duration of untreated psychosis and outcome in first-episode schizophrenia: A Critical Review and Meta-Analysis. [Miscellaneous Article]. *Am J Psychiatry*, 162, 1785-1804.
- Rogers, E.S., Chamberlin, J., Ellison, A.L. & Crean, T. (1997). A consumer-constructed scale to measure empowerment among users of mental health services. *Psychiatr Serv*, 48:1042-1047.
- Scully, P.J., Coakley, G., Kinsella, A., Waddington, J.(1997) Executive (frontal) dysfunction and negative symptoms in schizophrenia: apparent gender differences in 'static' v. 'progressive' profiles. *Br J Psychiatry*, 171, 154-158.
- Spencer, E., Birchwood, M., McGovern, D. (2001). Management of first-episode psychosis. *Adv Psychiatr Treat*, 7, 133-140.
- Teague, G.B., Bond, G.R., Drake, R.E. (1998). Program fidelity in assertive community treatment: development and use of a measure. *Am J Orthopsychiatry*, 68, 216-232.
- Trompenaars, F.J., Masthof, E.D.M., Heck van, G.L., Hodiamont, P.P.G., & Vries de, J. (2005). Content validity, construct validity, and reliability of the WHO QOL-BREF in a population of Dutch adult psychiatric outpatients. Qual Life Res, 14(1), 151-160.
- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. (2008a). Model fidelity of Assertive Community Treatment for clients with first-episode psychosis: a target group-specific application. *Community Mental Health J*, 45(1):12-18.
- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. (2008b). Cliënten als ervaringsdeskundig interviewer in wetenschappelijk onderzoek, De betekenis voor de kwaliteit van de verzamelde data en het herstelproces van de interviewers. Tijdschrift voor Rehabilitatie. [Client involvement in mental health research: effects on quality of data and on the recovery process of the interviewers. Dutch Journal of Rehabilitation].

- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., Garretsen, H.F.L. (2008c, in press); Effectiveness of Assertive Community Treatment versus care as usual in early psychosis: Results of a 2-year quasi-experimental outcome study. (In press).
- Vries, J. de, & Heck, G.L. van (1997). The World Health Organization quality of life assessment instrument WHO QOL-100: Validation study with the Dutch version. *Eur J Psychol Assess*, 13(3), 164-178.
- Weert-van Oene de, G.H., Buwalda, V.J.A., Havenaar, J.M., Swildens, W., Keijzerswaard van, A., Schrijvers, A.J.P., (2006). Demand-oriented care: the development and validation of a measuring instrument. *Soc Psychiatry Psychiatr Epidemiol, W41, 215-220.*
- Wijngaarden van, B & Schene, A.H. (1997). The Involvement Evaluation Questionnaire (European Version). *Amsterdam: Department of Psychiatry, University of Amsterdam.*
- Wijngaarden van, B., Schene, A. H., Koeter, M., et al. (2000) Caregiving in schizophrenia: development, internal consistency and reliability of the Involvement Evaluation Questionnaire – European Version: EPSILON Study 4. *Br J Psychiatry, 177,* s21 –27.
- Wowra, S.A., McCarter R. (1999) Validation of the Empowerment Scale with an outpatient mental health population. *Psychiatr Serv,* 50,959-961.

CHAPTER 7

COST-EFFECTIVENESS OF ASSERTIVE COMMUNITY TREATMENT VERSUS CARE AS USUAL FOR YOUNG PERSONS SUFFERING FROM EARLY PSYCHOSIS

Abstract

Objective

Having established that Assertive Community Treatment (ACT) is cost-effective for severely mentally ill clients, this study explores its cost-effectiveness in patients with first-episode psychosis.

Methods

Two Dutch mental healthcare institutions participated in this study. One institution provided ACT (N=105) and the other provided Care as Usual (CAU) (N=44). To estimate costs, all provided services were analysed. The primary selected effect measures were scores on the Global Assessment of Functioning (GAF) and the Clinical Global Impression scale (CGI). Results were calculated over a two-year period.

Results and conclusions

ACT proved to be a cost-effective intervention for patients with first-episode psychosis. Costs are significantly lower and effects (expressed in scores on the GAF and CGI) for ACT are significantly better than for CAU.

Objective

Healthcare budgets are limited, making it impossible to introduce all new technological developments and thus stressing the need to set priorities. To assist decision-makers in allocating their budgets, economic evaluations are considered important (Drummond, Sculpher, Torrance, O'Brien, & Stoddart, 2005; Grijseels, Koopmanschap, & Offringa, 2003). This principle also applies to healthcare services for persons who suffer from a first-episode psychosis. Some studies have explored the cost-effectiveness of Assertive Community Treatment (ACT) in Severely Mentally Ill (SMI) patients. This study addresses the specific cost-effectiveness of ACT in persons with a first-episode psychosis.

Assertive Community Treatment

ACT is the most applied and most researched evidence-based practice in mental healthcare (Dixon, 2000). In several countries it has proven to be an effective and efficient treatment model for the group of patients mostly designated as SMI. The model was designed in the USA in the 1970s by Stein and Test. From the beginning they intended to create a model that offers SMI patients an alternative to hospitalization. The target group left the hospital and learned how to live in the community. Typical features of this model are: the attitude of the professionals is proactive and assertive, treatment takes place in the community, a multi-disciplinary team is responsible for a group of patients, and the team delivers all the services required.

Why ACT in early psychosis?

In first-episode psychosis it is considered important to intervene during the critical period (i.e. the first 3-5 years) and start treatment immediately after the first positive symptoms appear. This approach results in a more favourable outcome and has a positive effect on the long-term course of the illness (Jørgensen, et al., 2000; Petersen, et al., 2005; Singh, & Fisher, 2005; Verhaegh, Bongers, Kroon, & Garretsen, 2008; Wunderink, & Alexander, 2006). Having established the beneficial effects of ACT in SMI patients, it is feasible that persons with a first-episode psychosis may also benefit from ACT (Burns, Creed, Fahy, Thompson, & Tyrer, 1999; Jørgensen, et al., 2000; Rosenheck, & Neale, 2001).

Patients with a first-episode psychosis who are provided with ACT after a 'short duration of untreated psychosis' receive multidisciplinary and integrated care from the very beginning, so that positive results can be expected (Archie, 2006; Jørgensen, et al., 2000; Pelosi, & Birchwood, 2003). Both the number and duration of crises, and related hospitalizations, are expected to decrease, leading to increased patient satisfaction. Moreover, by helping to prevent crises and avoiding hospitalizations, ACT may have a positive effect on long-term psychosocial and cognitive functioning, thereby having a positive influence on cost-effectiveness on the longer term (Cuddeback, Morrissey, & Meyer, 2006; Yang, et al., 2005).

Is ACT expected to be more or less cost-effective than care as usual?

The cost-effectiveness of ACT has been shown in studies comparing this strategy with other forms of treatment. According to Dixon (2000) the chance that ACT is a cost-effective treatment increases when the costs of hospitalization are included in the analysis and when patients have extensive hospital use (at least 50 days per year in one study). The 3-year analyses conducted by Clark, et al. (1998) show that ACT tended to be less efficient during the first two years, but became significantly more efficient during the final year of that study. Thus, ACT efficiency appears to improve over time. The main reason for this is the smaller number of inpatient days with ACT (Clark, et al., 1998; Tunis, 1999). Wolff, et al. (1997) also demonstrated better client outcomes for persons who received ACT (compared to brokered case management) without additional costs; therefore, ACT was considered more cost-effective. Lehman, et al. (1999) compared Assertive Community Treatment (ACT) with Care as Usual (CAU). Their results show that ACT could be a cost-effective approach among the homeless with severe mental illnesses to increase their time spent in stable housing.

Economic evaluation

According to Drummond, et al. (2005) economic evaluation is *"a comparative analysis of alternative courses of action in terms of both their costs and consequences"*. This means that the basic tasks of economic evaluations are identifying, measuring, valuing and comparing costs and consequences of the alternatives being considered.

In the present study we chose for a cost-effectiveness analysis (CEA). CEA is a full economic evaluation: it concerns both costs and benefits/effects and makes comparisons with appropriate alternatives (Drummond, et al., 2005; Grijseels, et al., 2003; Uyl-de Groot, 2001).

We chose the perspective of an extrawelfarism approach, which focuses on how to allocate healthcare resources from a healthcare organisational perspective. It considers the healthcare resources consumed and compares them with the health improvement obtained in two or more programs (Drummond, et al., 2005).

Costs are expressed in money (euros), and effects in scores on the Global Assessment of Functioning (GAF) and the Clinical Global Impression scale (CGI).

Methods

Two mental health institutions (both located in the southern part of the Netherlands) participated in the present study: the institute in Eindhoven (GGzE) provides ACT (the experimental condition) and the institute in Tilburg (GGzMB) offers CAU (the control condition). The institutions have a similar catchment area of about 450,000 inhabitants and have comparable socio-economic and demographic features (Verhaegh, et al., 2008).

Experimental and control condition

ACT in the experimental condition offers a multidisciplinary team approach and provides integrated intensive care (treatment, plus support geared to patients with co-morbid disorders) in a pro-active way. The staff/patient ratio is 1:10 (Verhaegh, 2008). The ACT team provides most of the services directed at all dimensions of daily life. Most services are provided within the community, and seldom within the hospital. Outside of normal working hours, the ACT team is supplemented by a crisis intervention service (including a shared electronic patient file system and crisis intervention plan). During the weekend one of the ACT staff can be reached by phone. The entire ACT team has daily briefings. The services of ACT consist of: cognitive behavioural therapy, psycho-education (family and client groups), treatment elements of integrated double-diagnosis treatment, individual placement and support (vocational training and school support), support for housing and financial issues, social support, pharmacotherapy, peer group support, and individual support from a peer group worker.

In the control condition (CAU), the administration of treatment occurs by way of 'stepped care'. This means that, in the first instance, the client is offered the treatment that is considered to be the most effective, with the least burden, and (depending on the nature and gravity of the situation) in the cheapest and shortest way possible. If this intervention proves to be insufficiently effective, a more intensive form of intervention is selected (Meeuwissen, & Weeghel, 2003; Davison, 2000). Clients generally are referred by a general practitioner or via crisis intervention services to a psychiatrist and/or a social psychiatric nurse. Together, they draw up a treatment plan and thereafter most patients receive low-intensive outreach care and day/part-time treatment. In case problems arise, the patient or the community/carers or a professional staff member can request to upgrade the care. This means that some patients receive temporary additional outpatient services, such as cognitive behavioural therapy or family treatment. In case those treatment arrangements also prove to be insufficient, day treatment or inpatient care (crisis intervention) is available. Some patients also receive additional help from the local authority (e.g. to find a suitable job or home), or parallel treatment for their substance abuse.

The control condition partially consists of the same services as offered in the experimental condition, but does not provide peer support, double diagnosis services, housing support, vocational training and school support.

Additional differences between the two models were objectified by the scores on the Dartmouth ACT Scale (DACTS) (Teague, Bond, & Drake, 1998) that establishes the fidelity to the ACT model. The DACTS score of ACT was 4.2, indicating a good fidelity to the ACT model. In contrast, the DACTS score of CAU was 2.4, indicating a low fidelity (Verhaegh, 2008).

Target groups

Everyone who received specialised mental healthcare for first-episode psychosis was potentially included in the study, except those patients who had drug-related or postpartum psychoses. The patients were selected based on the DSM-IV codes.

Inclusion for *the experimental group* started in January 2005 by including those patients who were already in treatment at that moment. These patients had their first-episode psychosis in the year prior to the inclusion date. The ACT group increased over time based on normal intake. The last client was included in the study in November 2006. Thus, data collection took place over a 3-year period. The follow-up period of each patient is 2 years.

All clients of *the control group* were already receiving treatment at the moment of inclusion (October 2006). These patients were included from an electronic database and no additional clients were added to the database after October 2006. Some data were required retrospectively for the period that these patients were already in treatment since their first positive symptoms, and for a few patients we completed the 2-year data set in July 2008.
For 10 patients (experimental group 6 and control group 4 patients) we had to extrapolate the available data over the remaining period (maximum of 2 months) to complete the 2-year treatment period for all included patients. Here we used a linear extrapolation method (Oostenbrink, 2003).
Besides describing characteristics of the total group of clients, we compared the two groups for the DSM-IV subtypes of 'Schizophrenia' and 'Psychotic Disorder, Not Otherwise Specified'. The first subgroup is considered to be the most seriously mentally ill and therefore consumes the most services (inpatient care); the second subgroup is selected because it is also highly prevalent among both our target groups. This breakdown provided insight into the proportion of these subtypes expressed as a percentage of the total group.

Effects

We chose to use Global Assessment of Functioning (GAF) and Clinical Global Impression (CGI) scores as the primary effect measure. This effect measure was chosen because the measures represent general expressions of psychiatric functioning. In this study we also pay attention to secondary effects of ACT that explain cost differences between the two conditions, non-in patient days and use of part-time and day-treatment facilities.

The GAF is a single-item rating scale for clinicians to rate the overall psychosocial functioning of patients; it has 10 anchor points and continuous scores ranging from 1-100 (Endicott, et al., 1976).
The CGI is designed to assess the global severity of illness and change in the clinical condition over time. The scale consists of 3 global subscales: Severity of illness, Global improvement, and Efficacy index. The Dutch version used in the present study consists of the first two subscales only (Nolen, 2008).

For both groups these data were obtained from professionals that filled out (retrospectively) a form consisting of a GAF score and a CGI score. Scoring the GAF is considered routine work because it is part of completing the DSM-IV diagnosis. All professionals received similar training to enhance the reliability of their diagnosis. Concerning the CGI scores, the professionals received an instruction guide prepared by the first author. In this way we enhanced the inter-rater reliability of the control group data. In the experimental group, the team psychiatrist completed all the questionnaires. In the control group 9 persons were involved in completing 44 questionnaires.

Care consumption data were acquired from electronic patient records of the two participating mental healthcare institutions. These institutions provide the vast majority of specialized mental healthcare for the target group. We did not include care from other care providers (addiction care, sheltered living, general hospital psychiatric units). However, on inquiry it appeared that in both groups this was very limited and, when it had occurred, it was to a similar extent in both conditions. ACT provides elements of an Integrated Double Diagnosis model. It occurred only once that a patient was admitted to an external crisis ward due to drug misuse. In CAU some patients were referred to ambulatory treatment for their addiction problems. In both groups, their first crisis intervention generally involved admission to a general hospital, thereafter if they relapse they are usually admitted to crisis intervention beds of the own organization. This patient group obviously seldom uses sheltered living facilities; they mostly live autonomously or with their parents.

Costs

To estimate costs in both conditions, a bottom-up approach was used that provides care consumption of the individual patient (expressed in inpatient days, day/part-time treatment, and activities performed by individual professionals). Inpatient days and day/part-time treatment are expressed in fixed prices per unit. The cost prices of ambulatory activities depend on which type of professional performed the activity. We used nationally fixed prices for the mental healthcare professions (CONO, 2008) that include salary costs and specific overhead costs expressed in euros per minute. Table 1 shows some examples of these costs.

Table 1. Examples of cost prices of the offered services

Kind of treatment	Cost price 2006/unit (€)	Cost price 2008/minute (€) (including overhead costs)
Inpatient day	260	
Part-time treatment	130	
Day-treatment (in groups)		0.31
Psychiatrist		2.37
Psychotherapist		1.71
Social psychiatric nurse		1.28
Consultation (private psychiatrist)		1.32
Occupational therapy, in groups		0.31

Statistical analyses

Analyses were performed using SPSS 14.0. The one-way repeated measures ANOVA test was used to test the differences in improvement between the groups on GAF and CGI scores over the two-year period (controlled for different baseline scores).

Based on earlier research we hypothesized that, compared to CAU, ACT would result in equal or better mental and social functioning (expressed in higher scores on the GAF and CGI scales) and/or equal or less costs. In those cases we used one-sided tests (in all other cases two-sided tests were performed).

The level of significance in all tests was set at a p-value <0.05.

Results

Characteristics of the target group (Table 2)

The target group comprised 149 patients: 105 in the experimental group and 44 in the control group. The average age of the total population was 26 years; 76% was younger than 35 years. The age of the patient was determined on the date that ACT and CAU commenced, i.e. shortly after remission of the client's first psychosis. No statistical significant differences were found between the groups for gender and age. DSM-IV classifications between the two groups showed some differences. The control group consists of more patients diagnosed with schizophrenia or subtypes (38%) compared to the experimental group (25%). In the other prominent group of patients diagnosed with Psychotic Disorder NOS, there is a reverse distribution, 32% in the control group and 42% in the experimental group.
At baseline the control group scored higher on the job/school characteristic. Of those in the control group, 45% had a job or went to school versus 34% of the experimental group. At baseline, more patients in the experimental group lived on their own (51%) than those in the control group (38.6%). More patients in the control group lived with their parents (38.6%) than members of the experimental group (31%). In the experimental group 10% were looking for an independent living facility versus 2.3% in the control group. Of the experimental group 8% was admitted or lived in a house for sheltered living compared with 20.5% in the control group. At baseline, the control group showed a similar level of "good/moderate social adjusted" (92%) as the experimental group (93.3%).

In this study to determine the Duration of Untreated Psychosis (DUP) we took the moment patients got involved in specialized mental health treatment (e.g. psychiatric ward of an general hospital or crisis ward of a psychiatric hospital). The moment patients got their first psycho-pharmaceutical treatment was mostly not traceable and also retrospectively difficult to assess whether the provided medication was adequately in the then situation. For that reason the here assessed DUP's are just indicative and must be interpreted as defined by Craig, et al. (2002). Furthermore in this study we couldn't determine DUP score of control group patients. In the experimental condition the DUP shortened over 4 years from 3 months in 2004, at the start of the ACT treatment, till 2 months in 2008.

Table 2. Characteristics of the ACT and the CAU (control) group at baseline

	ACT (n=105)	CAU (n=44)
Gender		
Male	82 (78.1%)	31 (70.5%)
Female	23 (21.9%)	13 (29.5%)
Age (years)		
Mean	26.3 (SD 8.1)	25.3 (SD 8.5)
Range	16-52	17-54
DSM-IV		
295.xx[1]	26 (24.8%)	17 (37.7%)
298.9[2]	44 (41.9%)	14 (31.8%)
DUP	Median = 3 months	-
Job/school		
Yes	8 (8%)	9 (21%)
With IPS or support	27 (26%)	11 (24%)
No (occasionally)	39 (37%)	14 (31%)
Not ready	30 (29%)	10 (24%)
Housing		
yes, own	53 (51%)	17 (38.6%)
Yes, with parents	32 (31%)	17 (38.6%)
Looking for own	10 (10%)	1 (2.3%)
No, admitted/sheltered	9 (8%)	9 (20.5%)
Social adjusted		
Yes	64 (61.9%)	31 (70%)
Moderate	33 (31.4%)	9 (21%)
No, cause trouble	7 (6.7%)	4 (9%)

[1]Schizophrenia and all subtypes

[2]Psychotic Disorder, Not Otherwise Specified

Global Assessment of Functioning and Clinical Global Impression (Table 3)

Over the 2-year period the GAF score of both groups improved significantly. The mean score of the ACT group increased from 40.5 at baseline to 50.9 after 2 years ($p<0.0005$). In the control group the score increased from 44.2 at baseline to 48.1 ($p=0.009$) after 2 years.

The mean baseline GAF score was significantly higher in the control group compared to the experimental group (44.2 vs. 40.5, $p= 0.02$); after 1 and 2 years the differences in GAF scores between the two groups were smaller and were not significant.

The improvement in GAF score between the groups over the 2-year period (controlled for the different baseline scores) was significant in favour of the ACT patients (Wilk's Lambda = 0.92,

F (2, 143) = 5.98, p= 0.003, multivariate partial eta squared = 0.077). The test shows that there was a linear-type improvement over time.

Table 3. Scores and differences on the GAF and CGI at baseline, at 1 and 2 years

	GAF at baseline	GAF at 1 year	GAF at 2 years	One-way repeated measures ANOVA
ACT (n=102)	40.5 (SD 11.9)	45.7 (SD 14.5)	50.9 (SD 14.5)	F = 5.98
CAU (n=44)	44.2 (SD 6.0)	46.9 (SD 7.9)	48.1 (SD 6.0)	P= 0.003
	CGI at baseline	CGI at 1 year	CGI at 2 years	One-way repeated measures ANOVA
ACT (n=98)	4.60 (SD 1.22)	3.63 (SD 1.37)	3.10 (SD 1.41)	F = 6.95
CAU (n=44)	4.09 (SD 0.99)	3.57 (SD 1.13)	3.39 (SD 1.47)	p= 0.001

Significance level p<0.05

The CGI improved (i.e. a decrease in score) over the 2 years. Both groups showed a significant improvement on the CGI scale: i.e. the scores of the ACT group decreased from 4.60 to 3.10 and those of the CAU group from 4.09 to 3.39 (both p<0.0005).
The mean baseline CGI score was significantly lower (= better condition) in the CAU group compared to the ACT group (4.09 vs. 4.60, p= 0.008); after 1 and 2 years the differences in CGI scores between the two groups were smaller and not significant.
The improvement in the CGI score between the groups over the 2-year period (controlled for the different baseline scores) was significant in favour of the ACT patients (Wilk's Lambda = 0.91, F (2, 139) = 6.95, p= 0.001, multivariate partial eta squared = 0.091). The test shows that there was a linear-type improvement over time. From the eta score we conclude that the effect size of these improvements (GAF 0.92 and CGI 0.91) is moderate (Cohen, 1988).

Number of non-inpatient days and use of day-treatment

In the control group, the average total number of non-inpatient days[1] during the 2-year study period was 660 per client; this means that on average a client stayed 35 days per year in a psychiatric hospital. The number of inpatient days during the first year was much higher than in the second year (55 and 18 days, respectively). Compared with the yearly average, in the first 3 months the average number of inpatient days was strikingly high (Table 4).

Table 4. Average number of non-inpatient days

Non-inpatient days	ACT group (n=105)	CAU group (n=44)	T-test (1-sided) (Sig. level p<0.05)
3 months (90 days)	86	61	0.001
Year 1	347	310	0.001
Year 2	354	351	0.69
Total over 2 years	702	660	0.007

[1] Non-inpatient days are defined as those days on which a patient was not hospitalized.

In the experimental group, the total number of non-inpatient days during the 2-year period was 702 per patient; on average a patient stayed 14 days per year on a psychiatric hospital bed. Also in this group the difference between the first and second year of treatment was large (18 and 11 days, respectively). During the first 3 months, the number of inpatient days in the ACT group was much smaller than in the control group (5 vs. 30 days).
In the first and second year, and over the 2-year period, the average number of non-inpatient days was higher in the experimental group; however, not all the differences are significant (Table 3).The numbers of non-impatient days in the second year are almost equal for both groups.
In the second year, the control group consumed (€ 273,780) much more day and part-time treatment than in the first year of treatment. In the experimental group part-time and day-treatment are not available.

Costs for provided services

The total costs for treatment of clients in the control group amount to € 41,589 per patient over a two-year period. This includes all costs for this client (salary of professionals, medication, inpatient treatment days). In the first 3 months after the first-episode psychosis the costs are € 3,827, after the first year € 20,196 and in the second year € 21,393.
The total costs for the experimental group amount to € 24,714 per patient over a two-year period. This means that the costs for ACT are significantly less than for CAU. ACT costs € 4,026 for the first 3 months, € 14,551 for the first whole year, and € 10,163 for the second year.

Table 5. Average costs (in euros) of ACT and CAU per patient over the first 3 months, 1st year, 2nd year and in total

	ACT	CAU	T-test (1-sided) (Sig. level p<0.05)
3 months	€ 4,026	€ 3,827	0.42
1st year	€ 14,551	€ 20,196	0.045
2nd year	€ 10,163	€ 21,393	0.001
Total over 2 years	€ 24,714	€ 41,589	0.002

In the control group the costs over the 2-year period rose slightly (+6%) despite a reduction of inpatient days. After 3 months the difference in costs for the two groups is not significant. The differences between the costs of both groups after one year and after two years are significant (Table 5).

Discussion and conclusions

Discussion

This study compared two similar groups of patients to assess the effects of ACT (the experimental condition) versus 'care as usual' (the control condition) and relate those effects to the costs of both conditions. Using a cost-effectiveness analysis, costs are expressed in money (euros) and effects in GAF and CGI scores.

The effects (GAF and CGI scores) of this study are convincing and showed that the experimental group, after both 1 year and 2 years of treatment, had a significantly better outcome.

Compared with the control group, the significantly more non-inpatient days in the experimental group is an important cause (39%) of the differences in costs made in the first year. In the second year there are an equal (much decreased) number of inpatient days in both conditions. This result is of particular importance for the patients and their families.
By the second year, in the experimental condition costs had decreased significantly whereas costs in the control group had increased by 6%. An explanation for this might be that GAF scores of the control group indicate a more severe psychosocial condition, which could be related to more intensive use of part-time and day treatment. Alternatively, this could reflect successful ACT interventions focused on preventing the loss of social roles and maintaining or regaining work and/or school in the first year of psychosis. A deliberate decision was made in ACT not to provide part-time and day treatment. In the second year the control group consumes for € 273.780 of part-time and day treatment. This explains 55.4% of the cost differences between the two groups in the second year.
The employment and school rates after two years of treatment support this explanation.
At baseline 45% of the control group and 34% of the experimental group had a job or went to school. After 2 years, 28% of the control group members and 49% of the experimental group went to school or had a job. From an extrawelfarism perspective this means an underestimation of the differences in real cost made for the two groups.

In the first 3 months of treatment the costs were higher in the experimental group despite a much lower number of inpatient days. This is due to the intensive service delivery of ACT (additional assessments, and outreach focused on prevention of crisis, work and/or school) during this early stage of treatment.
It is debatable whether all the patients in the present study should be treated with ACT for 3-5 years after the appearance of their first positive symptoms. Some argue that ACT should be indicated for only the most severely ill patients, which could imply that the remainder of the group is receiving too much care and attention. The other side of the medal is that it remains

difficult to predict in the first few years (after the critical period) which patients will be diagnosed as belonging to the category of Schizophrenia subtypes (chapter 5); also in the present study almost half (42%) of the experimental group consisted of patients diagnosed with a Psychotic Disorder NOS. This means that a definite diagnosis has not yet been made and that (when excluded from the target group) the risk of a wrong indication and/or not receiving appropriate care is considerable. Furthermore arguing patients tend to ask for unnecessary intensive mental healthcare starts from a debatable point of view. We haven't experienced this phenomenon, in the contrary, patients want to work, go to school and live in normal social circumstances.
Finally, a selection of only the subgroup with the most severely mentally ill patients (when possible) yields practical problems in organizing an autonomic service for such a small group within Dutch mental healthcare.

In the present study, the significantly increased GAF and CGI scores in the first and second year indicate that ACT is more effective in the experimental group than CAU in the control group.

The GAF and CGI scores and school/work rates demonstrate that ACT patients in the second year consume less care because they are again able to fulfil their previous social roles to a greater extent. In the ACT group the linear improvement in GAF and CGI scores, higher work/school rates, and increased non-inpatient days also in the second year might indicate the start of a reduced need for mental healthcare in the long term. An increased number of inpatient days in the first year in the control group explained the differences in costs in the first year. In the second year the difference in costs (despite fewer inpatient days) of 55.4% can be attributed to the day-treatment provided.

Thus, combining these two outcomes shows a better effect and lower costs of ACT versus CAU, which implicates that ACT is a more cost-effective treatment compared to CAU.

Limitations of the study

Different types of economic evaluations are available. A cost-utility analysis has the advantage that effects are expressed in Quality Adjusted Life-Years (World Health Organisation, 2007), which makes outcome data more comparable. However, due to the absence of such data, we chose for the second best alternative, a cost-effectiveness analysis (CEA). In addition, it is more desirable to perform a CEA from a societal perspective. In this study the CEA is performed from an extrawelfarism perspective, because there were insufficient resources to measure all relevant costs. This probably resulted in an underestimation of the real cost differences between the two conditions; other cost savings and/or long-term effects were not included (e.g. additional parallel-treatment costs for substance abusers, or for patients who dropped-out of school/work, and for the expected long-term reduction of healthcare consumption) (Clark, et al., 1998).

In this study we also excluded costs made for sheltered living because this rarely happened and if so, it was used to the same extent in both conditions.

Moreover, our results were probably also underestimated because the effect of the care for the substance abusers (control group patients) is now attributed to the CAU. In the present study, when a patient was offered ambulatory services in an external organisation for substance abusers, the effect was attributed to CAU; in ACT there are no ambulatory parallel treatments for addicted patients.

Although the control group included a relatively small number of clients, both groups were comparable regarding their main characteristics, with the exception of the number of patients in the subgroups diagnosed with Schizophrenia and Psychotic Disorder NOS. A possible explanation for this was that patients in CAU could stay longer in a ward of a hospital and/or in an acute care setting of the Tilburg institute. This causes a delay in transfer to the treatment settings from which we included the control group. This could be an explanation for the larger number of patients diagnosed with the Schizophrenia subtypes. Our data confirm these assumed explanations. The numbers of patients diagnosed with Schizophrenia and with Psychotic Disorders NOS was indeed almost the same in both groups, except that they have a different, reverse distribution. Another explanation could be the different use of the DSM-IV; the control group patients may have received their diagnosis in the schizophrenia spectrum earlier in their stage of illness.

The baseline scores of the GAF and CGI in the control group were better than those of the experimental group. This could be due to a lack of inter-rater reliability, or to the assertiveness of the ACT treatment that keeps all admitted clients in the case load (dropout over the 2-year period is 5%). This could result in the absence of non-motivated patients and patients with a low compliance (associated with lower GAF scores) in the control group. A third reason for the difference at baseline is the short transfer period in the experimental condition versus a longer period of transfer from acute services to the treatment setting (were the baseline GAF and CGI assessments were performed) in CAU. The two groups also differ regarding school/job rates (CAU at baseline had better scores), whereas for housing circumstances ACT scored better (due to "not hospitalizing" treatment policy) and on social adjustment the groups scored equally well.

Unfortunately no system is available to check the quality and completeness of all the collected data. However, Dutch mental healthcare institutions depend on the accuracy and completeness of their registration of delivered services for their finances. Thus, it is of vital importance to them that they register all activities. Therefore, we assume that the quality of the data in both organisations is good.

Conclusions

ACT was earlier demonstrated to be a cost-effective treatment for severely mentally ill clients. We hypothesized that ACT could also be a cost-effective treatment for patients suffering from first-episode psychosis. The results show that costs were significantly lower for clients in the experimental group, i.e. the group which received ACT. In the first year the cost difference is mainly attributable to a higher degree of hospitalization in the control group. In the second year there were equal numbers of non-inpatient days (which has substantial implications for patients and their caregivers), but lower costs for ACT due to an intensive use of day-treatment programs in the control group.

The effects, expressed in GAF and CGI scores, were significantly better for ACT over the two-year period.

All these data allow us to conclude that ACT is a cost-effective treatment for the target group of patients suffering from a first-episode psychosis. Moreover, we assume that the current results are an underestimation of the actual difference in costs and effects between ACT and CAU, because we did not include societal costs that are in favour of ACT.

Future research

The present study population (particularly the CAU group) was relatively small. Future studies should include a larger group of patients with, preferably, a longer follow-up period which can reveal how costs and effects develop on the longer term; differences between the two treatment groups might then become even more apparent. Another, second best, option is to extrapolate these data to a longer term, in order to estimate how these costs and effects might develop.

It is generally preferred to express effects in Quality Adjusted Life-Years. Therefore, future studies should aim to systematically interview clients about the perception of their quality of life. To this end (and also to improve the quality of the services provided), quality of life should be one of the routine outcome measurements in mental healthcare.

In addition, it is recommended to use a broader societal perspective so that costs such as sickness absence and other long-term effects will also be included. People who can be treated in a more community-based way might be able to continue their school and/or work and maintain their social network, which could reduce the costs of sickness absence and enhance the quality of life.

Finally, future research should address the allocation of financial recourses in the earlier stages of sickness for those interventions that have proven effective.

References

- Archie, S., (2006). Integrated care improves one-year outcomes in first-episode psychosis. *Evidence-Based Mental Health,* 9 (2):46.
- Burns, T., Creed, F., Fahy, T., Thompson, S., & Tyrer, P., (1999). Intensive versus standard case management for severe psychotic illness: a randomised trial. *Lancet,* 353 (9171):2185-2189.
- Clark, R.E., Gregory, B., Teague, S.K., Ricketts, P.W., Bush, H.X., Thomas, G., McGuire, R.E., Drake, G.J., McHugo, A.M., Keller, & Zubkoff, M. (1998). Cost-effectiveness of Assertive Community Treatment versus Standard Case Management for Persons with Co-Occurring Severe Mental Illness and Substance Use Disorders. *HSR: Health Serv Res,* 33 (5):1285-1308.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.
- CONO: the national expertise centre for professions in mental health care in the Netherlands. Available from: http://www.conoggz.nl/html/home.htm, 2008.
- Cuddeback, G.S., Morrissey J.P., & Meyer, P.S. (2006). How Many Assertive Community Treatment Teams Do We Need? *Psychiatr Serv,* 57 (12):1803-1806.
- Davison, G.C. (2000) Stepped care: doing more with less? *J Consul Clin Psychol,* 68(4):580–5.
- Dixon, L. (2000). Assertive Community Treatment: Twenty-Five Years of Gold. *Psychiatric Services,* 51, 759-765.
- Drummond, M.F., M.J. Sculpher, G.W. Torrance, B.J. O'Brien, & G.L. Stoddart. 2005. *Methods for the Economic Evaluation of Health Care Programmes.* Third ed. New York: Oxford University Press.
- Endicott, J., Spitzer, R.L., Fleiss, J.L., & Cohen, J. (1976). The Global Assessment Scale: A procedure for measuring overall severity of psychiatric disturbance. *Arch Gen Psychiatry,* 33, 766-771.
- Grijseels, E.W.M., Koopmanschap, M.A., & Offringa, M. (2003) Economische evaluatie. In *Inleiding in evidence-based medicine.* Houten: Bohn Stafleu Van Loghum b.v.
- Jørgensen, P., Nordentoft, M., Abel, M.B., Gouliaev, G., Jeppesen, P., & Kassow, P. (2000). Early detection and assertive community treatment of young psychotics: the Opus Study. *Soc Psychiatry Psychiatr Epidemiol,* V35 (7):283-287.
- Lehman, A.F., Dixon, L., Hoch, J.S., Deforge, B., Kernan, E., & Frank, R. (1999). Cost-effectiveness of assertive community treatment for homeless persons with severe mental illness. *Br J Psychiatry,* 174 (4):346-352.
- Meeuwissen, J., & Weeghel, Van, J. (2003). Modulenboek bij het stepped care-programma voor depressie. Utrecht: Trimbos-instituut, Programma Diagnostiek & Behandeling.
- Nolen, W. (2008). Clinical Global Impression Scale, www.tijdschriftvoorpsychiatrie.nl/meetinstrumenten/download.php?id=29.

- Oostenbrink, J.B., Al, M.J., & Rutten-van Mölken, M.P.M.H. (2003). Methods to Analyse Cost Data of Patients Who Withdraw in a Clinical Trial Setting. *Pharmacoeconomics, 21 (15): 1103-1112.*
- Pelosi, A.J., & Birchwood, M. (2003). Is early intervention for psychosis a waste of valuable resources? *Br J Psychiatry, 182* (3):196-198.
- Petersen, L., Jeppesen, P., Thorup, A., Abel, M.B., Øhlenschlæger, J., Christensen, T.Ø., Krarup, G., Jorgensen, P., & Nordentoft, M. (2005). A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *BMJ*, 331: 602-5.
- Rosenheck, R., & Neale, M.S. (2001). A Critique of the Effectiveness of Assertive Community Treatment. *Psychiatr Serv,* 52 (10).1395-1396.
- Singh, S P., & Fisher, H.L. (2005). Early intervention in psychosis: obstacles and opportunities. *Adv Psychiatr Treat*, 11 (1):71-78.
- Teague, G.B., Bond, G.R., Drake, R.E. (1998). Program fidelity in assertive community treatment: development and use of a measure. *Am J Orthopsychiatr*, 68, 216-232.
- Tunis, S.L. (1999). The Impact of Schizophrenic Patient Functionality on Service Utilization and Cost. *Am J Manage Care*, 5 (10 Sup):583-590.
- Uyl-de Groot, C.A. (2001). Uitgangspunten en opzet van onderzoek. In *Van kosten tot effecten - Een handleiding voor evaluatiestudies in de gezondheidszorg.* Maarssen: Elsevier Gezondheidszorg.
- Verhaegh, M.J.M., Bongers, I.M.B., Kroon, H., & Garretsen, H.F.L. (2008). Model fidelity of Assertive Community Treatment for clients with first-episode psychosis: a target group-specific application. *Community Mental Health J,* 45(1):12-18.
- World Health Organisation (2007). Disability Adjusted Life Years (DALY), [cited June 5, 2007]. Available from http://www.who.int/healthinfo/boddaly/en/index.html.
- Wolff, N., Helminiak, T.W., Morse, G.A., Calsyn, R.J., Klinkenberg, W.D., Trusty, M.L. (1997). Cost-effectiveness evaluation of three approaches to case management for homeless mentally ill clients. *Am J Psychiatry*, 154 (3):341-348.
- Wunderink, A. (2006). Antipsychotic treatment strategies and early course of first episode psychosis. Dissertation, Rijks Universiteit Groningen, Groningen.
- Yang, J., Law, S., Chow, W., Andermann, L., Steinberg, R., & Sadavoy, J. (2005). Best Practices: Assertive Community Treatment for persons with severe and persistent mental illness in ethnic minority groups. *Psychiatr Serv,* 56 (9):1053-1055.

CHAPTER 8

DISCUSSION AND CONCLUSIONS

Introduction

In this thesis the effectiveness of Assertive Community Treatment in early psychosis was examined. The main question addressed in this thesis is: ... *does Assertive Community Treatment (ACT), provided to clients suffering from early psychoses during their critical period, show significantly better treatment effects regarding positive and negative symptoms, and clinical and social functioning, compared to the effects of Care as Usual (CAU) provided to a similar group of patients, also with regard to the costs incurred with both forms of treatment?*

The following questions, derived from the main research question, are addressed:

1. Does ACT meet the demands of the target group and how does the model get a target group- specific application?
2. Over a two-year treatment period, what effect does ACT have on patients who suffer from early psychoses compared to a similar group of clients who received CAU?
3. Over a two-year period, what effect (based on 4 outcome areas) does ACT have on the recovery process of patients who suffer from early psychoses?
4. Is ACT a cost-effective treatment model compared with CAU?

In this study we additionally addressed the following research question that appeared from special interest and concerns a particular way of data collection using client interviewers:

5. What influence do client interviewers have on the quality of the collected data and on the course of the interviews?

The next sections of this final chapter summarize the research findings and their impact (Results and Discussion), describe the limitations of the study (Limitations), draw conclusions and make recommendations related to daily practice and future study (Conclusions and Recommendatons).

Results and Discussion

Does Assertive Community Treatment (ACT) meet the demands of patients suffering from early psychosis and how does the model get a target group-specific application?

In chapter 3 it was shown that the ACT services were provided in a fully implemented way (i.e. according to the Dartmouth Assertive Community Treatment fidelity scale [DACTS]) (Teague, 1998), and then underwent adjustments over time to enable them to even better fit the demands of the local target group and their relatives/carers.

When ACT started within mental healthcare in Eindhoven in 2004, there was no evidence in the Netherlands that ACT and early psychosis could be a successful match. Mulder and Kroon (2005) presented arguments in favour of applying ACT to new target groups, such as patients suffering from early psychosis. Meanwhile, in the Netherlands many new early psychosis treatment programs started, most applying ACT as their treatment model. Mulder and Kroon (2005) strongly suggested to accompany the application or adaptation of evidence-based treatments by studies that determine the fidelity and effects of the program in the new circumstances. Experts of ACT, such as Bond and Drake (2007), are also open to suggestions and have also welcomed relevant changes to the model.
The adjustments made in Eindhoven were based on feedback from the individual patients and their carers about the ACT services provided. Adjustments made to the model were related to vocational training, school and financial support, and accessibility in the weekends and evenings. Psycho-education for families, and separately for patients, is an important service that also received more attention the first year after ACT was introduced.
Van Veldhuizen, et al. (2006) introduced Function ACT model as a variation on the original ACT model (FACT) in the Netherlands. Van Veldhuizen and colleagues have described their new model; this is an example of a practice- based innovation that will receive feedback and lead to further development. Unfortunately, at this moment we do not know (and this applies to all Dutch and most foreign initiatives) what the outcome is and what the new results can be attributed to.

Over a two-year treatment period, what effect does ACT have on patients who suffer from early psychoses compared to a similar group of clients who received Care as Usual (CAU)?

In chapter 5 it was found that on most of the outcome measures the ACT patients scored better compared to the patients receiving CAU. In both conditions (ACT and CAU), during the first weeks/months in most cases the most devastating symptoms (delusion and hallucinations) disappeared. Rapid recovery from first positive symptoms in mental healthcare

and in specific for specialised early psychosis services are general findings. In 1998, Birchwood, et al. reported: "... the potential benefits of early intervention include: reduced morbidity, more rapid recovery..." (Birchwood, et al., 1998). Also, Petersen (2005) states that a successful medication policy is a key element of treatment in early psychosis.
After 1 and 2 years both our groups showed a (linear-type) improvement, indicating that the effects evolved continuously over the 2-year period. There was a significantly greater improvement in ACT compared to CAU over 2 years of treatment and the largest proportion of the total effect sizes appeared in the first year of treatment. Other studies also found better results for specialized early psychosis treatment (Jeppesen, 2007; Craig, et al., 2004).

The number of inpatient days in the first year of treatment was much higher in CAU due to more and longer admissions in the first part of the patient's recovery process. From the beginning, a reduction of hospital beds has been reported (Stein, Test, & Marx, 1975). Later on, nearly all well-known projects reported a reduction in hospital use (Stein, and Santos, 1998; Dixon, 2000; Mueser, et al., 1998). Hospitalisation is sometimes inevitable; however, to avoid admissions being too long it is necessary to leave responsibility for admission and discharge to the CAU case manager. From the first day onwards, the case manager steers the process and focuses on discharge (Teague, 1998).

After 2 years most patients were successful in living in society and became socially adjusted to their environment. ACT showed a better performance in this area than CAU. Marshall & Lockwood (1998), in an effect study on ACT in patients with diagnoses of schizophrenia, also reported positive effects on social adjustment for ACT. They found less police contacts, less trouble in the environment and increased feelings of safety in society at citizens. Outcome data from early psychosis projects show that Family psycho-education and Multi-family groups (Dixon, 2000; Cuijpers, 1999; Petersen, 2005; Hazel, et al., 2004) are important with respect to social integration. In the present study we also found positive results from the ACT intervention (family group psycho-education) towards carers. This indicates that carers play a important role in the social networks; they often act as mediators or early detectors of signs that indicate danger.

Co-morbidity of psychosis and substance abuse is common in the target group of young patients suffering from psychosis; this was also the case in the present study. Despite the Double Diagnosis interventions included in ACT, substance abuse (especially drugs abuse) in the ACT group did not decrease. In contrast, drug abuse in CAU did decrease. In CAU substance abusers were treated in specialised parallel organised facilities. During the 2-year study period, alcohol misuse in the ACT group diminished slightly more than in the CAU group.
The results of the Opus study also showed minor effect of ACT on substance abuse (Petersen,

2007). In other studies the effect of early psychosis treatment on substance abuse was found to be more positive (Petersen, et al., 2007; Waldron, Turner, & Clin, 2008).
ACT in Eindhoven provided elements of the Integral Double Diagnosis model (IDD) (Drake, 1998), but did not implement the entire model according to the IDD-fidelity scale. This could be a reason of the disappointing result of Double Diagnosis treatment in ACT. The internal course leader from GGz Eindhoven that trains professionals in "integrated double diagnosis treatment" explained the disappointing result of the ACT-treatment on drugs and alcohol abuse by an increased awareness and detection at the beginning of the treatment. According to this specialist treatment efforts have a delayed effect. Because substance abuse is associated with psychosis and relapse, this part of the treatment needs to be improved.
We need to establish exactly why the specialised Double Diagnosis services are not yet very effective.

In the domain of housing no significant improvements were found over time for either of the groups. Also, there were no significant differences between the groups over the 2-year study period. The ACT group included more persons who live on their own, or work on this together with a professional specialised in housing. Petersen, et al. (2005) and Mueser, et al. (1998) found more effect of stable housing in specialized early psychosis treatments compared to CAU. In the present study support to find housing, and financing housing facilities, was an important issue. Carers and clients complained about a lack of support on those issues, and the ACT team now gives more attention to this item.

Compliance with medication and treatment in general is an important item. In this study the two seem to be communicating vessels. There appears to be a balance between drop-out from treatment and the medication policy. In this study we found a better treatment compliance and worse medication compliance for ACT compared to CAU. The LEO study in England (Garety, et al., 2006) and the OPUS study in Denmark (Petersen, 2005) reported enhanced compliance levels on both treatment and medication. ACT aims to develop a strong alliance between patients and carers. Professionals in ACT Eindhoven may give higher priority to treatment compliance and make more concessions regarding medication compliance. This might explain the better treatment compliance and worse compliance on medication.

Psychosis often is accompanied by losing jobs or dropping out from school. Over the 2-year study period, the improvement on work and school rates between the two groups (controlled for baseline differences) was significantly better for ACT. The in ACT applied IPS intervention follows the merit of "first place, then train". The intervention aims to remain jobs or to find paid jobs for patients. From the beginning, patients and carers asked for more attention to be paid to vocational training and school support. Patients need support to find custom-made solutions for their needs regarding school and job issues. Guidelines and study results stress

the importance of expertise for supported employment or education in early psychosis treatment because of their relation with self-esteem, day structure, financial independence and successful role functioning in general (International Early Psychosis Association, 2005; Collins, et al., 1998; Mueser, Salyers, & Mueser, 2001).

Over a two-year period, what effect (based on 4 outcome areas) does ACT have on the recovery process of patients who suffer from early psychoses?

From chapter 6 it appeared that patients do recover, but not all to the same extent or in the same period of time. From interviews, meetings and home visits it became apparent that the motivation and drive to recover by patients (and carers) was substantial. Many similarities in the recovery courses of patients and their carers emerged, e.g. patients and parents experience psychosis as being traumatic and very intrusive, meet problems regarding self-esteem, relationships, work, stigmatisation. It also was shown in literature that the process of recovering from a psychosis is unique for all individuals and their carers; every individual experiences his/her own emotions, way of coping, preferences of engagement and follows his/her own time schedule (Deegan, 1988, 1992, 1996; Boevink, et al., 2002).
The psychopathological functioning of the participating patients improved significantly after a few months. The same results are reported by others (Stein, & Test, 1980; Burns, et al., 2001; Bertelsen, 2008). We also investigated whether patients experience improvements on their Quality of Life and Empowerment.

As stated in chapter 5 there were no satisfying improvements related to substance abuse (see above). In this section we address the importance of reducing substance abuse in relation to recovery. Patients talk freely about their substance abuse and its consequences. Some patients are aware of the risks of using drugs and alcohol, and mention it as being a reasoned choice. They prefer drugs because of the positive effects on side-effects of medication and on their feelings. In line with our experiences, Petersen and colleagues (2007) reported that patients are well informed about drugs and are aware of the effect of triggering psychotic symptoms.
Data and interviews demonstrated how important carers are, how intensively they are involved in the recovery process of their son/daughter or partner and how much stress this can cause (see Recommendations: 'Involving carers and preventing their burden'. Over the 2-year study period the intensity of being a carer remained stable whereas the impact of the contacts caused significantly less burden to the carers. This is thanks to the carers themselves on the first place, and also to professional interventions, and to the recovery achievements of the patients. Other studies also underline the importance of family involvement and strategies that make carers' involvement possible and easier for all parties (IEPA writing group, 2005; Roick, et al., 2007; Cuijpers, 1999; Hazel, et al., 2004).

In this study ACT achieved much better efforts in vocational and educational recovery of patients (see Recommendations: 'Vocational and educational support') than CUA. Patients and carers indicated that structuring the day and having meaningful paid day activities are very important. Additional investments in vocational training and educational support staff, and extra focus on this area, yielded an almost 50% work/school rate after 2 years of treatment in the ACT group. Other studies report the positive influence of early interventions on vocational and educational recovery, but show less improvement than the present study (IEPA writing group, 2005; Roick, et al., 2007; Cuijpers, 1999; Hazel, et al., 2004).

Is ACT a cost-effective treatment model compared with CAU?
This part of the study (chapter 7) was designed to find out how effects are related to costs for the both conditions. With regard to cost-effectiveness, large cost differences were found in favour of ACT. Concerning effects, ACT scored better on primary effect measurements, i.e. Clinical Global Impression (CGI) and the Global Assessment of Functioning (GAF). Our findings are supported by earlier studies where ACT also proved to be less costly and/or more cost-effective (Kuipers, et al., 2004; Weisbrod, Test, & Stein, 1980; Marshall, & Lockwood, 1998).

In the first year of our study, the cost difference was explained (39%) by the higher admission rates in CAU. The community-oriented preventive attitude proved its effect and resulted in less and shorter admissions for ACT patients in the first year . This finding is common in early intervention studies; from the beginning Stein and Test (1995) found decreased hospital use (Birchwood, et al., 1998; Dixon, 2000; Stein, & Santos, 1998; Craig, et al., 2004; Garety, et al., 2006). Results in the second year show much higher rates of part-time and day treatment for CAU. This explained 55.4% of the cost differences between the two groups. It illustrates that most patients do not need prolonged day-time and/or part-time treatment when there are more effective and cheaper alternatives, such as social role fulfilment at home as family member, in society as friend, or at work/school as employee or student.

This insight in relation to cost-effectiveness can be meaningful. Until now studies have focused on what should be done to improve outcome. An interesting point of view in cost-reduction policy could also be: what should we 'stop doing' because it was proven not effective, or is relatively cost-ineffective.

What influence do client interviewers have on the quality of the collected data and on the course of the interviews?
Client involvement in this study was an additional subject and appeared to be meaningful and promising. There were no significant differences between data obtained from client interviewers or non-client interviewers. However, the interviewees reported that they felt more

comfortable and could speak easier with client interviewers. This form of client participation yields interviews and data with a comparable level of quality as when performed by non-client interviewers. Earlier studies reported better quality (more valid) of data when obtained by client interviewers (Simpson et al., 2003; Clark, et al., 1999; Dietzen, & Bond, 1993; Faulkner, & Thomas, 2002). Participating in research often implies accurate and stressful work. For clients this could result in stress and could contribute to a relapse. In our study a relapse occurred only once, but we found no direct relationship with the research activities.

Limitations of this study

In this section we describe the encountered limitations of the study. First we address general limitations of the study (the design and data collection) and then we address specific limitations addressed in chapters of the thesis.

Design

The experimental and control group were compared on baseline characteristics in order to examine similarity. At baseline the two groups differed with regard to diagnostic labels and scores on the GAF and CGI. The differences in diagnostic labels could be caused a lack of inter-rater reliability between Eindhoven and Tilburg. Another explanation could be the assertiveness of the ACT treatment that keeps all participating clients in the case load (dropout over the 2-year period is 6%). In the control group, this could result in a nearly absence of non-motivated patients and patients with a low treatment compliance (associated with lower GAF scores). However, it is more likely that the difference had to do with the different timing of the baseline measurements. In the control group baseline measurements took place on average 2 months after admission of the patients (maximum treatment period on a crisis ward is 3 months); at that moment the patients were included in the control group. In the experimental group baseline measurements took place on average 3 weeks after their admission. Normally, patients improve most in the first 2 weeks after their first psychosis due to the antipsychotic medication. In both groups we excluded this very early period. This reduces the baseline differences considerably.

Another point of concern is that the relatively small numbers of participants may have caused some statistical underpowerment. Although many outcomes of the experimental and control group showed significant (large) improvements over the 2-year study period, the differences between the two groups were not always significant. However, most non-significant results point in the same direction, i.e. in favour of ACT. Same is found in similar studies indicated that the results might have become significant with larger numbers of participants.

Data collection

This study used four methods of data collection: 1. data collection by interviews performed by client or not-client interviewers (chapter 4), 2.data collection by examining patient files (chapter 5 and 6), 3. professionals interviewing patients using questionnaires (chapter 5 and 6), and 4. obtaining data from registration databases (chapter 7).

Data collected by professionals (third data collection method) may have been biased due to an over-enthusiastic attitude of ACT team members towards the new intervention. From the start, expectations were high and the team members were very enthusiastic. We tried to minimize the bias by controlling the data collected by ACT team members and training the professionals.

All questionnaires that were completed with support from ACT team members were scored by the main investigator. Professionals received all a training with regard to completing Health of Nation Outcome Scale (HoNOS) and Positive and Negative Syndrome Scale (PANSS), and during the study period the team members and the main researcher regularly 'practiced' dealing with cases to enhance reliability. At those meetings, the reliability was shown to be good. Inter-rater reliability scores were not determined.
The GAF and CGI scales were completed by professionals. In Tilburg the case manager of each particular patient (11 persons) completed the GAF and CGI scores (partly retrospectively) because they were the best informed about the baseline status of the client. In Eindhoven one person (the psychiatrist) completed all the GAF and CGI scores. Every rater received instruction and, in most cases, the completion of the scales (GAF, PANSS, and HoNOS) is part of their regular job.

Bias could be in favour of the experimental results due to the new ACT project. However this is an implicit goal of the model. A shared caseload and implementing evidence based practices intend to enhance enthusiasm and team spirit.

Quality and completeness of collected data
Unfortunately no system is available to check the quality and completeness of all the collected data. However, because Dutch mental healthcare institutions depend on the accuracy and completeness of their registration of delivered services for their finances, it is of vital importance that they efficiently register all activities. Therefore, we assume that the quality of the data in both organisations is good and at least of equal quality.

The data we obtained from medical files (chapter 5) were not entirely complete or correct because the file/recording system of the CAU changed to an electronic system; during the transfer period some weeks showed a break in the continuity of information. We later checked for correctness by asking professionals if the collected data were correct and complete; when required we either added or corrected the data. In both conditions (experimental and control) we did not have full insight into the external admissions of patients, e.g. ward of a general hospital. We have no indication whether this has biased the data.

Limitations related to specific chapters
Compliance with medication was explored, and the percentage of patients that initially used antipsychotic medication was determined (ACT 94% and CAU 96%). To ensure that the results could not be attributed to a different medication policy, we noted the policy concerning antipsychotic medication. In both conditions, psychiatrists followed the guidelines of modern pharmacotherapy (Dutch Guidelines for Schizophrenia, 2005). However, based on our enquiry

we could not determine whether all details of the policy were carried out in exactly the same way in both conditions.
During the 2 years of treatment the ACT condition evolved and changed, based on evaluations and feedback received from the patients and their carers it got target group-specific application. Therefore ACT was not fully implemented from the very beginning (chapter 4). This might imply an underestimation of the effects found. On the other hand, the ACT group was not fully sized from the beginning; in that early period the professionals had more time to spend with their patients which might, in total, have neutralized the former effect.

In spite of our definition of 'suicidal behaviour' the data for this area were perhaps biased due to inconsistent use of the definition. During the process of data collection we noticed an under-registration of suicidal incidents. Professionals tended to interpret suicidal behaviour as 'temporary risky behaviour', without registering such incidents.

In this study the cost-effectiveness analysis is performed from an extrawelfarism perspective because there were insufficient resources to measure all relevant costs. The amount of (in this study not included) those extra costs could be up to 30% of the total costs (Wolff, 1995). This probably resulted in an underestimation of the real cost differences between the two conditions; other cost savings and/or long-term effects were not included (e.g. additional parallel-treatment costs for substance abusers in the control group, or for control group patients who dropped-out of school/work, and for the expected long-term reduction of healthcare consumption due to better treatment outcome in the first two years) (Clark, et al., 1998). In this study we also excluded costs made for sheltered living because this rarely happened and, if so, it occurred in both conditions to the same extent.

Conclusions and Recommendations

Conclusions

The overall conclusion from this study is that ACT appeared to be an adequate treatment model for patients in their early phase of psychosis. The model provides enough flexibility for target group-specific applications without losing model fidelity.

Young people suffering from early psychosis recover very quickly; in most cases a first crisis can be controlled with pharmacotherapy within one or two weeks. In the ACT condition, in the first treatment year most patients receive intensive care and from the beginning the focus is on preventing (further) loss of role functioning. If this should nevertheless occur, it is dealt with immediately. CAU acts in a more reactive way, when problems occur then the additional services are provided. Care administration is based on stepped care principles.

Most ACT patients demonstrated that they can, to a considerable extent, resume their social roles (work, school, leisure, and friends) very soon (generally within 6 months) after their first-episode psychosis. Generally it is not necessary to transfer patients after the initial phase to a part-time or day treatment program. A long delay before returning to one's normal roles carries the risk of hospitalisation. ACT is better organized and better equipped than CAU to quickly perform services that meet the patient's needs and help them avoid social exclusion.

This study allows us to conclude that patients (and carers) have that motivation and spend much energy in the recovery process. Sometimes the drive and energy were temporarily absent due to negative symptoms, depressions or disappointments. In those circumstances carers and professionals are most the obvious persons to support and, when necessary, act assertively. Of all the different courses of recovery, we conclude that there is always hope and new opportunities for success (Farkas, 2005; Salyers, 2007). For professionals this means a challenge to improve their skills, remain strong and optimistic, and act pro-actively.

This recovery outcome study has shown that ACT contributes to a successful recovery process of young people suffering from psychosis; patients make quick improvement regarding psychopathology, gaining and regaining social roles, and quality of life and empowerment. Carers play an important role in supporting their children/partners and are key figures in the social (safety) network.

In this study ACT proved to be a cost-effective intervention for patients suffering from psychosis. Costs are significantly lower and the effects (expressed in non-inpatient days and GAF scores) for ACT are significantly better compared with CAU.

Recommendations for further research

In this study we find linear-type improvement measures (GAF and CGI) that develop over a 2-year period. We would like to know: 1. how the present ACT patient group develops during their critical period, because expected long term effects of early intervention services (e.g. lower care consumption is supposed to be a long term effect of treatment) (Clark, et al., 1998), and 2. when (based on what prospective criteria) should patients be transferred to which type of follow-up treatment?

The effect of provided Double Diagnosis interventions was disappointing. We suggested a few possibly explanations and it would be interesting to investigate the explanation for the absence of effects of the double-diagnosis treatment?

In this study carers showed to be key figures in community care for young persons suffering from early psychosis. Research questions in this area are: "What is the main role of carers in the recovery process", "How can carers be prevented from carers' burden" and "What is the impact on siblings when a brother or sister gets a psychosis?"

Healthcare more and more is driven, not only by evidence practices, but also by costs and the relationship between costs and effects. Till now in mentalhealth there are no adequate outcome measures that enable cost-utility studies. A research question from this perspective would be: "How to facilitate cost-utility research (instead of cost-effectiveness research)? and "How to facilitate cost-utility research from a broader societal perspective (including sickness absence and other long-term effects)?

A larger study population (with at least 100 patients per group) is necessary in order to have sufficient statistical power to establish more (significant) effects in similar comparative studies. Not only the statistical significance is of importance; we also should examine what clinical relevance the findings represent.

The experimental condition in this study is ACT. This is a well-described model and relies heavily on fidelity requirements. We determined that some target group-specific applications did not negatively influence the fidelity of the ACT model (chapter 3). We did not investigate the contribution made by each specific element or type of service to the results. Nor did we distinguish between the organisational part of ACT and the applied interventions of the professionals, to determine the contribution made by these elements to the results. In this study we considered ACT to be an integrated treatment model whose total is more than the sum of its parts. Nevertheless research on most effective parts of the ACT model could be useful.

Recommendations for daily practice

Involving clients in research

In this study we involved client-interviewers in research and find that their collected data had the same quality as data collected by non-client interviewers. Patients preferred to be interviewed by client interviewers because according to patients, especially in the psychotic phase, client interviewers are capable to understand what patients try to explain and patients feel more comfortable when interviewed by client interviewers. We also want to recommend the use of client interviewers in performing research tasks. However, we also recommend to replicate this study with a larger study population.

Avoiding delay in adequate early psychosis treatment

Duration of Untreated Psychosis (DUP) is usually described as the period starting from the first positive psychotic symptoms up to the moment the patient receives treatment. Adequate treatment often involves the provision of pharmacotherapy (Skeate, Jackson, Birchwood, & Jones, 2002; Norman, & Malla, 2001). In the present study we defined the DUP in the same way, except for the interpretation of 'adequate treatment'. Here, we took the moment the patient became involved in specialized mental healthcare treatment (e.g. a psychiatric ward of a general hospital, or crisis ward of a psychiatric hospital) (Craig, Bromet, Fennig, Tanenberg-Karant, et al., 2000).

In the literature DUP and the issue of (very) early detection is important (Archie, 2006; Jørgensen, et al., 2000; Pelosi, & Birchwood, 2003). A few governments (Dept. of Human Services, 2000; Dept. of Health, 2000) decided to introduce specialized early psychosis treatment thereby shortening the DUP. All guidelines for early psychosis consist of interventions to reduce the period from the emerging first positive symptoms to the first adequate treatment. The reason for that a short DUP is associated with better treatment outcome, better course of illness and less carers' burden (Nordentoft, et al., 2008). Most reviews and studies on DUP confirm those results, except for those professionals who have an ethical problem with very early detection (Vlaminck, 2003). Their biggest objection is that there is no validated detection instrument. The available instruments lack adequate psychometric features; they have sufficient sensitivity, but can not specify who is really at high risk and who is not. This might come to an ethical discussion as to where a line should be drawn between false-positive youngsters being confronted with mental healthcare, and preventing long-lasting psychiatric problems for some of the young persons detected.

There are more options to reduce the period between the first psychotic positive symptoms and the specialized early intervention services. First, it is possible to reduce the period from first contact with secondary mental healthcare to inclusion in an early intervention service. Professionals often tend to treat the young person themselves, not aware that they are withholding the patient from services that focus on a broader range of interests. This can

happen on crisis wards of psychiatric hospitals, or on psychiatric wards of general hospitals. The second possibility is to avoid a waiting list for new patients. This involves two points: organizing sufficient capacity, and clarifying who (and on what criteria) a patient can be dismissed from the specialized service to adequate follow-up treatment.

Involving carers and preventing their burden

It is shown that ACT makes a contribution to the successful recovery of young psychotic patients in the community. Community care in this target group presupposes a functional safety network. Caregivers, carers, relative, partners and friends are a conditio sine qua non for successful outreaching care. Without carers supporting, guiding, activating, motivating, stimulating, and preventing danger, it would probably not be possible to avoid patients being hospitalised, and enable patients to stay at school and maintain their jobs. Carers' involvement should be a basic feature of community care; the treatment team starts with the premise: "yes, unless....".

Involving carers (parents, siblings, friends, volunteers, peer group members, colleagues, et cetera) in the treatment of patients suffering from early psychosis is important from more than one viewpoint. Guidelines for treatment of early psychosis are unanimous about the importance of a social network that supports the patient to recover in community. Another point of view has an economic origin. Admission to a ward always includes the danger of hospitalisation, in the meaning of total institutionalisation where patients lose their responsibilities and adapt to the new system they are part of (Goffman, 1961). Another economic argument for treatment in the community by applying ACT services, is the availability of vocational and educational support that avoids loss of work or school. A third economic reason to apply ACT is the supposed long-term effect on the social functioning of patients and the related less consumption of care.

In this study, the Involvement Evaluation questionnaire yielded data that showed that carers, especially in the early phases of psychosis, experience stress that causes much burden (Jeppesen, et al., 2005). This influences their lives to a great extent. Carers indicate that they need (and receive) much support from ACT professionals (advice, psycho-education, and assertive interventions in case of danger). Conversely, professionals benefit from carers and consider them part of triad. In our opinion this is the primary focus of carers' involvement. Carers' involvement deserves a positive labelling. Intervention should be targeted on carers' involvement (important role in triad) instead of preventing burden.

There are some other points of special interest. Firstly, observations and reports from professionals show that not only the carers experience stress. Also siblings experience the consequences of a psychotic brother or sister; until now not much attention has been paid to this (Greenberg, Kim, & Greenley, 1997). A second point of interest is paying attention to associated success factors of family treatment. It is known that successful family involvement is most difficult

when the patient is male, has an ethnic background, and whose pre-morbid functioning and education is poor (Roick, et al., 2007). A third point of interest addresses friendships of patients. Clients often report that they lost many friends due to their psychosis. Friends do not understand what is happening, and are frightened and unaware of the impact of psychosis. ACT intervenes intensively in the primary system of the patient, and less in the broader networks. With regard to social integration and leisure activities more attention should be paid to this item. Education provided in schools, to the media, teachers and general practitioners, might enhance understanding, decrease the stigmatisation, and could contribute to maintaining social contacts.

Vocational and educational support

Work and school is important and is associated with quality of life. Work and school are common subjects to discuss e.g. at parties, on buses and in waiting rooms of general practitioners. In such a conversation the second question is often: what do you do? From this perspective everyone understands the meaning of having work or going to school; you have something (a job or an education) and you are someone (a student or an employee) that positively contributes to society. The same argument and thoughts apply to persons suffering from a psychosis. Probably even more because the disturbing influence of the psychosis. The interaction effects between psychosis and work/school is the rationale for professional interventions such as Supported Employment (e.g. Individual Placement and Support, IPS) or Supported Education (Dutch Guideline for Schizophrenia, 2005; Collins, et al., 1998; Mueser, et al., 2001).

In Eindhoven the ACT team started to provide both services (0.8 employees educated in IPS). At first, the ACT team was criticised by carers because of the insufficient capacity of both services. After two years the capacity increased from 0.8 to 1.5 fulltime equivalent, more attention is paid to supported education, and impressive results were achieved. The ACT team observed that patients like to go to work or school, but that this is often impossible due to their problems. In those cases, professionals try to influence this by medication and applying Cognitive Behavioural Therapy. When patients are able to go to work or school, professionals support in vivo: financing study, bringing a day structure (work-eat-sleep), providing skills training (applying for a job, writing a letter of application, etc.), and advising the patient about dilemmas (e.g. should I tell about my psychosis, or not?).

In supported education patients and professionals work together with the school to prevent drop-out and to arrange specific facilities when needed (short sessions, no group trainings in the beginning, additional lectures, etc.). The importance of successfully finishing education is obvious, especially when it is known to be a prognostic factor for vocational success (Kroon, & Van Erp, 2002).

References

- Archie, S., (2006). Integrated care improves one-year outcomes in first-episode psychosis. *Evidence Based Mental Health* 9 (2):46.
- Bertelsen, M., Jeppesen, P., Petersen, L., Thorup, A., Øhlenschlæger, J., le Quach, P., et al. (2008). Five-Year follow-up of a randomized multicenter trial of intensive early intervention vs standard treatment for patients With a first-episode of psychotic illness: the OPUS trial. *Arch Gen Psychiatry,* 65(7):762-771.
- Birchwood, M.,Todd, P., & Jackson, C. (1998). Early intervention in psychosis. The critical period hypothesis. *Br J Psychiatry,* 172 (suppl. 33), 53-59.
- Boevink, W., Van Beuzekom, J., Gaal, E., Jadby, A., Jong, F., Klein Bramel, M., Kole, M., Te Loo, N., Scholtus, S., & Van der Wal, C. (2002). Working together toward recovery. Utrecht: Trimbos-instituut.
- Bond, G.R., & Drake, R.E. (2007). Should we adopt the Dutch version of ACT? Commentary on: "FACT, the Dutch Version of ACT". *Commun Mental Health J,* 43, 435-438.
- Burns, T,. Fioritti, A., Holloway, F., Malm, U., & Rössler, W. (2001). Case Management and Assertive Community Treatment in Europe. *Psychiatr Serv,* 52: 631-636.
- Clark, R.E., Gregory, B., Teague, S.K., Ricketts, P.W., Bush, H.X., Thomas, G., McGuire, R.E., Drake, G.J., McHugo, A.M., Keller, & Zubkoff, M. (1998). Cost-effectiveness of Assertive Community Treatment versus Standard Case Management for Persons with Co-Occurring Severe Mental Illness and substance use disorders. *HSR: Health Serv. Res,* (5): 1285-1308.
- Clark, C.C., Scott, E.A., Boydell, K.M. & Goering, P. (1999). Effects of client interviewers on client-reported satisfaction with mental health services. *Psychiatric Services,* 50: 961-963.
- Collins, M.E., Bybee, D., & Mowbray, C.T. (1998). Effectiveness of supported education for individuals with psychiatric disabilities: Results from an Experimental study. *Commun Mental Health J,* 34, 595-613.
- Craig, T.J., Bromet, E.J., Fennig, S., Tanenberg-Karant, M., Lavelle, J., & Galambos, N. (2000). Is There an Association Between Duration of Untreated Psychosis and 24-Month Clinical Outcome in a First-Admission Series? *Am J Psychiatry,* 157:60–66
- Craig, T.K.J., Garety, P., Power, P., Rahaman, N., Colbert, S., Fornells-Ambrojo, M., & Dunn, G. (2004). The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *BMJ,* 329: 1067.
- Cuijpers, P. (1999). The effects of family interventions on relatives' burden: a meta-analysis. *J Mental Health,* 8:275-285.
- Deegan, P. (1988). Recovery: the lived experience of rehabilitation. *Psychosoc Rehabil J,* 11(4), 11-19.
- Deegan, P. (1992). The Independent Living Movement and people with psychiatric disabilities: Taking back control over our own lives. *Psychosoc Rehabil J,* 15, 3-19.
- Deegan, P. (1996). Recovery as a journey of the heart. *Psychiatric Rehabil J,* 19, 91-97.

- Department of Health (2000) The NHS Plan: A Plan for Investment. A Plan for Reform. London: DoH
- Department of Human Services (2000) Primary Mental Health and Early Intervention Services.Victoria: DoHS.
- Dietzen, L.L. & Bond, G.R. (1993). Relationship between case manager contact and outcome for frequently hospitalized psychiatric clients. *Hospital Community Psychiatry,* 44.9: 839-843.
- Dixon, L. (2000). Assertive Community Treatment: Twenty-Five Years of Gold. Psychiatr Serv, 51, 759-765.
- Drake, R.E., McHugo, G.M., Clark, R.E., Teague, G.B., Ackerson, T., Xie, H., & Miles, K.M. (1998). A clinical trial of assertive community treatment for patients with co-occurring severe mental illness and substance use disorder. *Am J Orthopsychiatry,* 68:201-215,
- Dutch Guideline for Schizophrenia [Multidisciplinaire richtlijn Schizofrenie; Richtlijn voor de diagnostiek, zorgorganisatie en behandeling van volwassen cliënten met schizofrenie (2005). Trimbos-instituut, www.ggzrichtlijnen.nl.
- Farkas, M., Gagne, C., Anthony, W.A., & Chamberlin, J. (2005). Implementing Recovery Oriented Evidence Based Programs: Identifying the Critical Dimensions. *Commun Mental Health J,* 41, (2), 141-158.
- Faulkner, A. & Thomas, P. (2002). User-led research and evidence-based medicine. *Br J Psychiatry,* 180: 1-3.
- Garety, P., Craig, T., Dunn, G., et al. (2006). Specialised care for early psychosis: symptoms, social functioning and patient satisfaction: randomised controlled trial., *Br J Psychiatry,* 188, 37-45.
- Goffman, E. (1961) Asylums. Essays on the social situation of mental patients and other inmates, Harmondsworth: Penguin, 1968. First published New York: Doubleday Anchor, 1961.
- Greenberg, J.S., Kim, H.W., & Greenley, J.R. (1997). Factors associated with subjective burden in siblings of adults with severe mental illness. *Am J Orthopsychiatry,* 67:231–241.
- Hazel, N.A., Mcdonell, M.G., Short, R.A., Berry, C.M., Voss, W.D., Rodgers, M.I., & Dyck, D.G. (2004). Impact of multiple-family groups for outpatients with schizophrenia on caregivers' distress and resources. *Psychiatr Serv,* 55:35-41.
- International Early Psychosis Association writing group (2005). International clinical practice guidelines for Early Psychosis. *Br J Psychiatry,* 187 (suppl. 48), 120-124.
- Jeppesen, P., Petersen, L., Thorup, A., Abel, M.B., Øhlenschlæger, J., Christensen, T., Krarup, G., Hemmingsen, R., Jorgenson, P., & Nordentoft, M. (2005). Integrated treatment of first-episode psychosis: effect of treatment on family burden: OPUS trial. *Br J Psychiatry,* 187 Suppl. 48, 85-90.
- Jorgensen, P., Nordentoft, M., Abel, M.B., et al. (2000). Early detection and assertive community treatment of young psychotics: the Opus Study Rationale and design of the trial. *Soc Psychiatry Psychiatr Epidemiol,* 35, 283-287.

- Kroon, H., & van Erp, N. (2002). Een sterke ketting, met zwakke schakels – onderzoek naar begeleid leren voor mensen met psychische beperkingen. Utrecht: *Trimbos-instituut*.
- Kuipers, E., Holloway, F., Rabe-Hesketh, S., & Tennakoon, L. (2004). An RCT of early intervention in psychosis: Croydon Outreach and Assertive Support Team (COAST). *Soc Psychiatry Psychiatr Epidemiol*, 39, 358–363.
- Marshall, M., & Lockwood, A. (1998). Assertive Community Treatment for those with severe mental disorders, *Cochrane Library*, vol. 5, no. 2.
- Mueser, K., Bond, G., Drake, R., & Resnick, S. (1998). Models of community care for severe mental illness: a review of research on case management. *Schizophrenia Bull*, 24, (1) 37-74.
- Mueser, K.T., Salyers, M.P., & Mueser, P.R. (2001). A prospective analysis of work in schizophrenia. *Schizophrenia Bull*, 27, 281-296.
- Mulder, C.L., & Kroon, H. (2005) Assertive Community Treatment. *Wetenschapelijke uitgeverij Cure & Care Publishers*, Nijmegen.
- National Early Psychosis Project Clinical Guidelines Working Party. (1998). *Australian Clinical Guidelines for Early Psychosis*. Melbourne: National Early Psychosis Project, University of Melbourne.
- Nordentoft, M., Thorup, A., Petersen, L., Øhlenschlæger, J., Christensen, T., Krarup, G., et al. (2008). Does a detection team shorten duration of untreated psychosis? *Early Interven Psychiatr*, 2, 22–26.
- Norman. R.M., & Malla, A.K. (2001). Duration of untreated psychosis: a critical examination of the concept and its importance. *Psychological Medicine*, 31:381-400.
- Pelosi, A.J., Birchwood, M. (2003). Is early intervention for psychosis a waste of valuable resources? *Br J Psychiatry, 182* (3):196-198.
- Petersen, L., Jeppesen, P., Thorup, A., Abel, M., Øhlenschlæger, J., Christensen, T., et al. (2005). A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *BMJ*, 331: 602-605.
- Petersen, L., Jeppesen, P., Thorup, A., Ohlenschlaeger, J., Krarup, G., Ostergard, T., Jorgensen, P., & Nordentoft, M. (2007). Substance abuse and first-episode schizophrenia-spectrum disorders. The Danish OPUS trial. *Early Interven Psychiatr*, 1 (1), 88–96.
- Roick, C., Heider, D., Bebbington, P.E., Angermeyer, M.C., Azorin, J.-M., Brugha, T,H., Kilian, R.. Johnson, S., Toumi, M., & Kornfeld, Å. (2007). Burden on caregivers of people with schizophrenia: comparison between Germany and Britain. *Br J Psychiatry*, 190, 333-338.
- Salyers, M.P., & Tsemberis, S. (2007). ACT and Recovery: Integrating Evidence-Based Practice and Recovery Orientation on Assertive Community Treatment Teams. *Commun Mental Health J*, 43 (6).
- Simpson, E.L., Barkham, M., Gilbody, S. & House, A. (2003). Involving service users as service providers for adult statutory mental health services. *The Cochrane Database of Systematic Reviews, Issue 4*.

- Skeate, A., Jackson, C., Birchwood, M., & Jones, C. (2002). Duration of untreated psychosis and pathways to care in first-episode psychosis: Investigation of help-seeking behaviour in primary care. *Br J Psychiatry*, 181 (43): 73-77.
- Stein, L.I., Test, M.A., & Marx, A.J. (1975). Alternative to the hospital: a controlled study. *Am J Psychiatry*, 132:517–522.
- Stein, L.I., & Test, M.A. (1980). An alternative to mental health treatment. I: Conceptual model, treatment program, and clinical evaluation. *Arch Gen Psychiatry*, 37, 392–397.
- Stein, L.L., & Santos, A.B. (1998). Assertive Community Treatment of persons with severe mental illness. New York, Norton.
- Teague, G., Bond, G., & Drake, R. (1998). Program fidelity in assertive community treatment: development and use of a measure. *Am J Orthopsychiatry*, 68, 216-232.
- Veldhuizen, van, J.R., Bähler, M., & Teer, W. (2006). FACT: de 'Functie ACT'. *Maandblad Geestelijke volkgezondheid*, 61, 525-534.
- Vlaminck, P. (2003). De moderne aanpak van psychose [Modern treatment in psychosis]. *Uitgeverij: Eburon, Delft*.
- Waldron, H.B., Turner, C.W., & Clin, J. (2008). Evidence-based psychosocial treatments for adolescent substance abuse. *Child Adolesc Psychol*, 37(1):238-261.
- Weisbrod, B.A., Test, M.A., & Stein, L.L. (1980). Alternative to mental hospital treatment: II. economic benefit-cost analysis. *Arch Gen Psychiatry*, 37:400–405.
- Wolff, N., Helminiak, T.W., & Diamond, R.J. (1995). Estimated societal costs of assertive community mental health care. *Psychiatr Serv*, 46: 898-906.

SUMMARY

Introduction

Mental healthcare for patients suffering from psychosis is always complex with multiple factors to be taken into consideration. Patients and their carers are confronted with several aspects of the psychosis, as well as with the consequences for their daily life. Many events that in earlier times seemed to be uncomplicated have become problematic for patients and their carers. Experiencing a first-episode psychosis is generally a major and far-reaching event for both the patients and their carers. In many cases the patients are not aware of what is actually happening to them and can not fully comprehend the consequences of their disorder, which often lasts for an extended period of time.

In the last decennia, much new knowledge on the aetiology, course and adequate treatment of psychoses has emerged and has been developed. One notable insight related to the treatment of early psychosis is the importance of early detection and intervention. The concepts of '(very) early detection' and 'Duration of Untreated Psychosis' (DUP) are prominent in this respect. Consensus as to what is considered 'adequate treatment', according to various guidelines and evidence-based practices, is also spreading. In the Netherlands, Assertive Community Treatment (ACT), a treatment model that in the last decennia has proven to be effective in the long-lasting mental healthcare for severely mentally ill patients, could be such an evidence-based practice.

Research question and design

The research question addressed in this study is: ... does Assertive Community Treatment, provided to clients suffering from early psychoses during their critical period, show significantly better treatment effects regarding their quality of life, psychosocial functioning, and psychopathology, compared to the effects of Care as Usual provided to a similar group of patients, also with regard to the costs incurred with both forms of treatment.

In a quasi-experimental design, the experimental group (ACT; Integrated Mental Healthcare Eindhoven and region the Kempen) is compared to an (almost) identical group of control patients that received CAU (mental healthcare Tilburg). Data were collected from each patient at three moments during a two-year period (i.e. at baseline, after 1 year, and at 2 years).

At the beginning of ACT in the Netherlands (2004), no scientific evidence was available regarding the adequacy of applying ACT to the target group of patients suffering from a first-episode psychosis. At that time there was convincing evidence for the effectiveness of ACT in the target group of severe mentally ill patients who need long-lasting and intensive treatment. Some foreign studies reported promising results after applying ACT to young patients suffering from early psychoses. In order to prove that ACT and early psychosis treatment in the

Netherlands yields an adequate match, the ACT team chose to apply fully implemented ACT according to a fidelity scale (the Dartmouth Assertive Community Treatment Scale). Based on the feedback of patients and carers the ACT model was tailored to the care demands of the target group and their carers. It was shown that the applications had no serious impact on the fidelity measurements over the two-year study period.

Results

The study explored variations in the way the original components of ACT were implemented for the new target group of clients with a first-episode psychosis (concerning work/school, finances, communication, and side-effects of medication) and determined that these variations lead the treatment model to a higher, more valuable, outcome level without losing fidelity of the model. The study describes how feedback from the participants enabled to achieve an optimally effective application of target group-specific treatment services. Findings in this part of the study show that ACT and early psychosis treatment is a successful match.

This study also addressed the involvement of clients in mental health research. The scores on a Quality of Life and Empowerment questionnaire, obtained from two subgroups of interviewers, were compared. In addition, the patients were asked whether it would have made a difference had they been interviewed by a client, or by a non-client interviewer, with regard to the truthfulness of their answers and the perceived course of the interview.
There were no significant differences between the data obtained from the two subgroups of interviewers. However, patients reported to feel more comfortable and to speak easier with client interviewers, especially in those phases of illness in which they experience the most psychotic symptoms.

Based on data obtained from patient medical files, differences in treatment outcome between ACT and CAU were established. ACT showed to be more effective on the following outcome measures: psychopathology (PANSS, CGI and GAF), psychosocial functioning (work/school, treatment compliance, social adjustment, alcohol abuse and consumption of inpatient facilities), and experienced quality of life (WHO-QoL and Empowerment). CAU showed to be more effective on the outcome measures "compliance to medication" and "drug abuse". No differences were found between the two groups on the outcome measures "living" and "suicidal behaviour".

In the present study, for the ACT group we established the impact of ACT on the recovery of patients. The results show that ACT contributes to a successful recovery process in young people suffering from psychoses. Patients improved quickly with regard to psychopathology, gain and regain of social roles, and showed improvement on quality of life and empowerment.

After two years, most results of ACT treatment were significantly better compared to the baseline measurements.

To establish whether ACT is also cost-effective when compared to CAU we estimated costs by analyzing all provided services over the two-year treatment period. The primary effect measures were patient scores on the GAF and on the CGI.
In this study ACT proved to be a cost-effective intervention for patients with early psychoses. Costs are significantly lower and effects (expressed in scores on the GAF and CGI) for ACT are significantly better than for CAU. In the control group (CAU) the increased number of inpatient days in the first year explained the differences in costs during the first year. In the second year the differences in costs were mainly attributed to the day-treatment provided in CAU. This explanation is supported by the employment and school rates after two years of treatment: at baseline, more members the CAU group had a job or went to school compared to the ACT group. After two years, much more members of the ACT group went to school or had a job compared to the CAU group.

Limitations of the study
Because in this type of study randomization was not an option, we had to choose for a quasi-experimental design. For this reason, although the two groups were similar they were not identical. Moreover, we were confronted with a delayed baseline measurement in the control group, which might have caused some of the baseline differences between the two groups.

Several types of data collection were used in this study. During the study we used several interviewers and paid considerable attention to inter-rater reliability. A possible bias in the process of data collection was the novelty effect in the experimental condition. From the beginning of the study the expectation of the ACT treatment was high and some of that high expectation might be reflected in the collected data. In the part of the study where ACT-team members collected research data this might have caused an overestimation of the results that were found in favour of the ACT group.

Conclusions and recommendations
The overall conclusion from this study is that ACT appeared to be an adequate treatment model for patients in their early phases of psychosis. The model provides enough flexibility for target group-specific applications without losing model fidelity. Treatment outcome was shown to be better for ACT on psychopathology, psychosocial functioning and experienced quality of life when compared to CAU.

In this study ACT also showed to be cost-effective. The effects of treatment were expressed in GAF and CGI scores; ACT scored significantly better than CAU. Also, ACT had fewer costs due to a lower consumption of inpatient treatment (first year) and less use of day-treatment (second year).

Young people suffering from early psychosis recover very quickly; in most cases a first crisis can be controlled with pharmacotherapy within a few weeks. In the ACT condition, during the first treatment year most patients received intensive care and from the beginning the focus was on preventing (further) loss of role functioning. Most ACT patients demonstrated that they can, to a considerable extent, resume their social roles (work, school, leisure, and friends) soon (generally within 6 months) after their first-episode psychosis.

The outcome of the recovery study shows that ACT contributes to a successful recovery process; patients make quick improvement with regard to psychopathology, gaining and regaining social roles, and quality of life and empowerment. Carers play an important role in supporting their children/partners and are key figures in the social (safety) network. Carers appreciate ACT-services for the positive impact it has on their burden.

We recommend further research to examine: 1) how the present group of ACT patients develops during their critical period in relation to the expected long-term effects of early intervention services, and 2) when (and based on what prospective criteria) should patients be transferred to which type of follow-up treatment?
Further investigation into the apparent absence of effect of the double-diagnosis treatment provided by ACT is also needed.
From a cost-effectiveness viewpoint we could also explore the following: how can we facilitate cost-utility research (instead of cost-effectiveness research)? and how can we facilitate cost-utility research from a broader societal perspective (including sickness absence and other long-term effects)?

Carers proved to be key figures in community care for young persons suffering from early psychosis. Research questions that remain to be addressed are: 1) what is the main role of carers in the recovery process, 2) how can carers be involved in a treatment triad, 3) how can carers be protected from carers' burden, and 4) what is the impact on siblings when a brother or sister suffers a psychosis?

In the ACT model we recommended to further explore the contribution made by the separate components and features (interventions as well as organizational aspects) to the treatment outcome.

For future new studies we recommend to use a larger population (at least 100 subjects) and to pay particular attention to practical relevance, as well as to statistical significance.

The following recommendations are made for ACT in daily practice:

1. Adequate treatment in early psychosis demands pro-active and quick interventions. Delay in adequate treatment can be avoided by shortening the Duration of Untreated Psychosis, organizing easy access to early psychosis services, and sufficient treatment capacity.
2. Carers should always be involved in the triad of patient-carer-professional in order to optimize the recovery process of the patient. Assertive treatment in the community depends on a functional social (carers) network. The main focus of professionals is on the triad of patient-carers-professional; to profit from this, it is recommended to prevent carers from too much stress and so-called "carer's burden". In addition, attention should be paid to all family members to avoid siblings from becoming traumatised.
3. Most patients suffering from early psychosis make a quick recovery from their psychopathology and are able to fulfil their social roles within one year after their first-episode psychosis. In young persons suffering from early psychosis, preventing drop-out from school or avoiding losing a job are very important elements in the process of making a successful recovery.

SAMENVATTING

Inleiding

De zorg voor patiënten met psychotische stoornissen is complex en meervoudig van aard. Patiënten en hun omgeving worden na het optreden van een eerste psychotische episode geconfronteerd met de verschillende aspecten van de ziekte maar ook met de hier aan gerelateerde consequenties voor het dagelijkse leven. Veel zaken die voorheen vanzelfsprekend leken, kunnen voor patiënten en hun omgeving problematisch worden. De ervaring van een eerste psychotische episode is voor patiënten en hun omgeving zeer indrukwekkend en erg ingrijpend. Vaak weten patiënten niet wat hen overkomt en zijn ze niet bekend met de consequenties van hun stoornis, die vaak een langdurig beloop kent.

In de afgelopen decennia is er veel nieuwe kennis ontwikkeld over het ontstaan, het beloop en de behandeling van psychotische stoornissen. Een van de meest belangrijke inzichten in de eerste-psychosezorg is goed en vroegtijdig interveniëren. Vroegtijdig interveniëren impliceert ook vroegtijdig opsporen van mensen met een (dreigende) psychotische stoornis. Begrippen als "early detection" en "Duration of Untreated Psychosis" (DUP) zijn binnen het gedachtegoed van eerste-psychosezorg van grote betekenis. Over wat adequate zorg inhoudt ontstaat in toenemende mate consensus, getuige richtlijnen en Evidence Based Practices. Assertive Community Treatment (ACT), een behandelmodel dat gedurende de afgelopen decennia bewezen heeft effectief te zijn in de langdurende zorg voor patiënten met ernstige psychotische stoornissen, zou voor de vroeg-psychosezorg in Nederland een dergelijke Evidence Based Practice kunnen zijn.

Onderzoeksvraag en- opzet

De onderzoeksvraag in dit onderzoek luidt: "Levert ACT, verstrekt aan patiënten met vroeg-psychose problematiek gedurende hun kritieke periode, significant betere behandelresultaten op (kwaliteit van leven, psychosociaal functioneren, psychopathologie) vergeleken met de effecten van Care as Usual (CAU) verstrekt aan eenzelfde doelgroep patiënten?". Tevens wordt de vraag beantwoord: "Is ACT kosteneffectief vergeleken met CAU verstrekt aan deze patiënten?". De experimentele groep patiënten kreeg de ACT behandeling en werd bij Geïntegreerde Geestelijke Gezondheidszorg Eindhoven en de Kempen (GGzE) geïncludeerd en is (in een quasi-experimenteel onderzoeksdesign) vergeleken met een vrijwel overeenkomstige controlegroep patiënten bij GGZ Midden-Brabant die de CAU behandeling kreeg aangeboden. De vergelijking is gemaakt op basis van drie metingen over een behandelperiode van twee jaar. Van alle deelnemende patiënten van beide groepen zijn, aan het begin van de behandeling, na een jaar en na twee jaar, onderzoeksdata verzameld.

Toen het onderzoek startte (in 2004) was er in Nederland geen wetenschappelijk bewijs beschikbaar dat aantoonde dat het toepassen van ACT bij de doelgroep van patiënten met een eerste psychose aangemerkt kan worden als een adequate behandelvorm. Wel bestond er

overtuigend bewijs dat ACT aangemerkt kon worden als een "Evidence Based Practice" voor de doelgroep "Severe Mentally Ill" en lieten buitenlandse eerste-psychose zorgprogramma's op basis van ACT veelbelovende eerste resultaten zien.
Om aan te tonen dat ACT en eerste-psychosezorg ook in de Nederlandse situatie een goede match is, werd er voor gekozen ACT in een zuivere vorm toe te passen en op geleide van feedback informatie van betrokken partijen (hulpverleners, patiënten en mantelzorgers) aan te passen aan de specifieke zorgvraag van de doelgroep. Gedurende de onderzoeksperiode is er jaarlijks een fidelity-meting uitgevoerd (met de Dartmouth Assertive Community Treatment Scale, DACTS) om objectief vast te stellen of het ACT-aanbod voldeed aan de hieraan gestelde kwaliteitseisen.

Resultaten
Gedurende het onderzoek zijn op basis van feedback van patiënten en mantelzorgers aanpassingen aan het ACT-model gedaan (meer nadruk op werk/school, communicatie, financiën en bijwerkingen van medicatie) die beter tegemoet kwamen aan de zorgbehoeften van de doelgroep. De aanpassingen hadden geen betekenisvolle invloed op de DACTS-scores, terwijl de tevredenheid van patiënten en mantelzorgers toenam. Op grond van deze bevindingen kan geconcludeerd worden dat de zorgvragen van patiënten met een eerste psychose en het ACT-aanbod een goede match vormen.

Bij de dataverzameling (Quality of Life en Empowerment vragenlijsten) werd gebruik gemaakt van ervaringsdeskundige interviewers. De verkregen data werden vergeleken met de data verkregen door niet-ervaringsdeskundige interviewers en vertoonden geen verschillen. Ook werd het verloop van de interviews vergeleken tussen de beide typen interviewers. Hier bleek dat er door cliënten voorkeur gegeven werd aan interviews afgenomen door ervaringsdeskundige interviewers omdat cliënten vonden dat deze gesprekken gemakkelijker verliepen; ze hoefden minder moeite te doen om duidelijk te maken wat ze bedoelden. Vooral gold dit voor cliënten die in een begin fase van hun herstelproces zaten en nog veel last hadden van psychotische belevingen.
Op grond van dossieronderzoek werden de CAU- en ACT-groep met elkaar vergeleken en werden (significant) betere resultaten gevonden voor ACT op de uitkomstmaten: psychopathologie (PANSS, CGI en GAF), psychosociaal functioneren (werk/school, behandeltrouw, sociale aanpassing, alcohol gebruik en gebruik van klinische voorzieningen) en de ervaren kwaliteit van leven door patiënten (WHO-QoL en Empowerment). CAU toonde betere behandelresultaten op "medicatie trouwheid" en "drugsgebruik". Voor de uitkomstmaten "wonen" en "suïcidaal gedrag" werden geen significante verschillen gevonden tussen de beide groepen.

De ACT-groep werd onderzocht op de mate waarin ze in de onderzoeksperiode vorderden in het herstelproces. Jonge mensen met een vroege psychose bleken al snel te verbeteren op psychopathologie en herstelden ook in termen van kwaliteit van leven en de mate waarin ze

weer grip kregen op hun eigen leven (QoL, Empowerment). Het psychosociaal functioneren na 2 jaar ACT-behandeling was eveneens significant beter dan bij de start van de behandeling.

Ten slotte zijn behandelresultaten (CGI- en GAF-scores) vergeleken en gerelateerd aan kosten gemaakt voor de beide onderzoekspopulaties. In het eerste jaar bleken de effecten uitgedrukt in CGI en GAF beter voor ACT en waren de kosten significant lager voor ACT. De belangrijkste verklaring hiervoor was een minder frequent en korter gebruik van klinische voorzieningen. In het tweede jaar was het klinisch zorggebruik genivelleerd maar was het kostenverschil verder opgelopen. De voornaamste reden voor dit verschil was het gebruik van deeltijd en dagbehandeling door leden van de controlegroep. Dit resultaat wordt ondersteund door resultaten op de uitkomstmaat "werk en school". Het percentage van de controlegroep dat "at baseline" werk had of naar school ging, was hoger dan dat van de ACT-groep. Na twee jaar behandeling was een aanmerkelijk hoger percentage van de ACT-patiënten aan het werk of ging naar school in vergelijking met de controlegroep.

Beperkingen

In deze effectstudie is gebruik gemaakt van een quasi-experimenteel design. Er kon geen randomisatie plaatsvinden, waardoor de groepen wel vergelijkbaar waren maar niet op alle kenmerken identiek bleken te zijn. Bij leden van de controlegroep was er bovendien sprake van een verlate baseline meting, waardoor mogelijk een deel van de baseline verschillen kan worden verklaard.

De wijze van dataverzameling in deze studie is divers geweest. Er zijn verschillende interviewers actief geweest waardoor inter-beoordelaars betrouwbaarheid steeds een belangrijk aandachtspunt was. Een mogelijke factor die de verzamelde data vertekend heeft, is het feit dat van ACT in de experimentele conditie veel verwacht werd, waardoor de objectiviteit van de scores op de vragenlijsten ingevuld door ACT-medewerkers beïnvloed kan zijn. Dit zou een overschatting van de gevonden resultaten voor de ACT-groep tot gevolg kunnen hebben gehad voor dat deel van het onderzoek waar sprake was van data verzameld door ACT-medewerkers.

Conclusies en aanbevelingen

Het onderzoek toont aan dat vroeg-psychosezorg volgens een (modelzuiver) op doelgroep-specifieke zorgbehoeften aangepast ACT-model betere resultaten oplevert op de uitkomst-domeinen: psychopathologie van de patiënten, hun psychosociale functioneren en de zelf beleefde kwaliteit van hun leven, vergeleken met de behandelresultaten van CAU. Tevens wijst de studie uit dat de ACT-behandeling kosteneffectief is vergeleken met de behandeling die de controlegroep heeft gekregen. De effecten (uitgedrukt in scores op CGI en GAF) waren significant beter voor de ACT-groep en de kosten waren significant lager voor de ACT-groep. De verklaring in het kostenverschil in het eerste jaar is een lager gebruik van klinische voorzieningen en in het tweede jaar is het kostenverschil toe te schrijven aan een grotere

zorgconsumptie van dagbehandeling en deeltijdbehandeling door de controlegroep. Patiënten uit de experimentele groep blijken snel te herstellen van hun eerste psychotische episode en blijken in staat weer snel het proces van psychosociaal herstel op te pakken. Patiënten geven aan dat de kwaliteit van hun leven en het regie voeren over hun eigen leven na 2 jaar behandeling significant toegenomen is. Mantelzorgers vervullen een belangrijke rol in de behandeling en ervaren de ACT-zorg als ondersteunend en verlichtend.

Als vervolg op dit onderzoek wordt aanbevolen onderzoek te doen naar de effecten van ACT over een langere periode (na 5 jaar, het einde van de kritieke periode, en na 10 jaar). Ook is onderzoek nodig naar de wijze waarop een zorgvuldige overplaatsing naar een adequate vervolgbehandeling kan geschieden. Vervolgonderzoek is eveneens gewenst naar het (uitblijven van) effect van geïntegreerde behandeling van comorbide (psychose-verslaving) problematiek. Een vervolgonderzoeksvraag vanuit het oogpunt van een kosteneffectiviteit zou kunnen zijn: "Hoe kan kosten-utiliteitsonderzoek vanuit een veel breder maatschappelijk perspectief gefaciliteerd en uitgevoerd worden in de Nederlandse Geestelijke Gezondheidszorg?".
Het belang van mantelzorgers in de zorg aan patiënten met vroeg-psychose problematiek is evident, echter de precieze rol en verantwoordelijkheid in het herstelproces van de patiënt is niet uitgediept. Vragen als: "Hoe kan overbelasting voorkomen worden?" en "Hoe kan aandacht geschonken worden aan het effect van een psychotisch gezinslid op broertjes en/of zusjes?" zijn in dit kader van belang. Vervolgonderzoek zou ook gedaan kunnen worden naar de specifieke invloed van ieder van de verschillende elementen van ACT (verschillende interventies en organisatorische kenmerken). In het algemeen geldt dat de vervolgonderzoeken grotere onderzoekspopulaties dienen te bevatten. Er dient naast statistische significantie, expliciete aandacht besteed te worden aan de praktische relevantie van de gevonden resultaten.

De volgende aanbevelingen worden gedaan om de kwaliteit van de vroeg-psychosezorg te verbeteren. Van belang bij de zorg voor patiënten met vroeg-psychose problematiek is dat proactief, snel en adequate zorg geboden wordt. Vertraging kan voorkomen worden door de DUP te verkorten, de instroom laagdrempelig te organiseren en voldoende behandelcapaciteit te realiseren.
Mantelzorgers dienen vanaf het begin altijd (tenzij, ...) betrokken te zijn bij het herstelproces van de patiënt. Om de patiënt in zijn eigen omgeving te kunnen laten hertellen is een intact sociaal netwerk noodzakelijk. De primaire focus van het behandelteam is dan ook de triade van patiënt- mantelzorger-hulpverlener. Om de triade optimaal te benutten, is het belangrijk dat mantelzorgers (ouders, partner, vrienden) niet overbelast raken of verwaarloosd worden.
Patiënten die kampen met psychotische problemen herstellen in de meeste gevallen snel van psychopathologische verschijnselen en kunnen ook snel weer, met begeleiding, hun sociale rollen hervatten. Intensieve behandeling en begeleiding bij het voorkomen van schooluitval en verlies van werk is een belangrijk thema bij deze groep jongeren.

EEN WOORD VAN DANK

Het was 2004 toen Geïntegreerde Geestelijke Gezondheidszorg Eindhoven en de Kempen (GGzE) academiseren als thema opnam in haar meerjaren- beleidsplan. De toenmalige voorzitter van de Raad van Bestuur, Dr. P.A.H. Verbraak was mede initiatiefnemer en stond aan de wieg van het realiseren van een Geestelijke Gezondheidszorg die haar zorg meer "evidence based" wilde laten zijn. In samenwerking met het departement Tranzo van de Universiteit van Tilburg en GGZ Midden-Brabant (later sloot zich bij dit samenwerkingsverband ook GGZ Breda aan) ontstond de Academische Werkplaats Geestdrift waar ik voor het eerst als werknemer kennis maakte met de academische wereld en in het bijzonder met het vraagstuk hoe Practice Based Evidence, Evidence Based Practice en Experience Based Evidence met elkaar verbonden zouden kunnen worden. De heer Verbraak, mijn toenmalige baas, adviseerde mij, om de rol van coördinator in deze Academische Werkplaats vanuit GGzE goed te kunnen vervullen, zelf een promotiestudie te starten.

Nu, na ruim vier jaar, is het moment daar om hem als eerste dank te zeggen voor zijn stimulerende advies. De weg van het opstellen van een onderzoeksprotocol tot het moment van afronden van de studie was vermoeiend en regelmatig voorzien van hobbels en gaten maar vooral ook mooi, avontuurlijk, uitdagend en verrassend. Bovenal was het een reis waar ik van genoten heb en waar ik met veel genoegen op terugkijk.
Hoewel het afleggen van de weg voornamelijk een solotoer is, is het onmogelijk de reis alleen tot een goed einde te brengen. Ik wil derhalve een aantal personen dankzeggen die in de afgelopen vier jaar gefungeerd hebben als: wegenwacht, rij-instructeur, bijrijder, vluchtstrook, tankstation, navigatiesysteem of garage.
In een of meer van deze hoedanigheden hebben allereerst de leden van mijn promotieteam gefunctioneerd. Zo was Inge Bongers als copromotor steeds nabij en betrokken. Haar aanwezigheid en deskundigheid gaven vertrouwen en op momenten dat mijn aandacht afdwaalde en scherpte verminderde, zette Inge de zaak weer op de rails. Zij toonde haar veelzijdigheid door enerzijds begrip, geduld en vertrouwen uit te stralen en anderzijds te hameren op planning, academische mores, doorgaan en afmaken; waarbij ze haar rode pen rigoureus, maar weldoordacht, door de manuscripten liet gaan. Inge, jij bent in staat iemand vertrouwen te geven, te laten geloven in zichzelf en het beste eruit te halen. Je complimenten waren goed getimed; je energie en enthousiasme waren voelbaar echt en stimulerend; je vakkundigheid leverde altijd een inhoudelijke meerwaarde.
De tweede copromotor, Hans Kroon, was op grotere fysieke afstand betrokken, en toonde zich gedurende het gehele promotietraject een, zowel inhoudelijk als methodologisch, zeer bekwaam professional. Ik heb je ervaren als een betrokken, positief kritisch en prettig persoon. De voortgangsbijeenkomsten kenmerkten zich als serieus, zakelijk "to the point", maar steeds

met een relativerende, nuancerende en humoristische lardering. Je toonde je betrokkenheid en deskundigheid ook in je snelle reacties op toegestuurde stukken en adviezen. Na een korte periode van aftasten en kalibreren ervaarde ik een verdere groei in de contacten; er was sprake van inhoudelijke fine-tuning en de samenwerking verliep soepel en aangenaam.
Ten slotte een woord van dank gericht aan mijn promotor, Henk Garretsen. Voor mij heb jij steeds de helicopter-view gehad en toonde je je zeer bekwaam in het sturen en bijsturen van zowel de inhoud als het proces. Jouw deskundigheid en betrokkenheid verdienen respect en zijn tevens illustratief voor de ambiance en werkcultuur binnen het geheel van het department Tranzo. Het was wel even wennen om een zo gelouterde professor en baas ook te leren kennen als een mens van vlees en bloed. Ook in die hoedanigheid heb je veel voor mij betekend en heb ik erg van je genoten. Natuurlijk mag jouw (en onze) grote Persoonlijke Sportieve Voorkeur voor voetbal niet onvermeld blijven.
In een adem met jou, Henk, noem ik Tranzo en al haar medewerkers, student-assistenten, stagiaires, secretaressen, promovendi en hoogleraren, die een mediterraan academisch klimaat met elkaar in stand houden dat werken, studeren en promoveren aangenaam maakt. Naast alle successen van de afgelopen jaren, waren er ook teleurstellingen en moesten we afscheid nemen van collega's die hun ambities niet konden realiseren. Het grootste verlies echter was het overlijden van collega Joop van den Bogaard. Joop, je was en bent voor mij een voorbeeld van een begenadigde wetenschapper die gewoon met 2 benen op de praktijkgrond bleef staan, een echte science practitioner. Ik baal er van dat het ons niet gegund is samen het glas te heffen. Joop bedankt!

Een tweede groep mensen die ik dank verschuldigd ben zijn de professionals en cliënten van zowel GGzE alsook GGZ Midden-Brabant. Zonder hun inzet was het niet mogelijk geweest het onderzoek tot een goed einde te brengen. Professionals toonden zich enthousiast en bereidwillig wanneer hen gevraagd werd medewerking te verlenen en ook actief bij te dragen aan het verzamelen van data. Regelmatig echter was ook voelbaar dat professionals wel wilden deelnemen, maar soms niet in die gelegenheid waren vanwege hun toegenomen druk op productie van cliëntenzorg. De medewerkers van het ACT-team waren altijd gastvrij, bereid mij te woord te staan en leverden een belangrijk aandeel in de dataverzameling. Soms had ik weer het gevoel deel uit te maken van een team maar dan sprak het geweten van de onderzoeker en nam ik de professionele distantie weer in acht.
In het bijzonder wil ik hier Ilse Dietvorst noemen die haar masterstudie aan de Erasmus Universiteit te Rotterdam gewijd heeft aan een kosten-effectiviteitsonderzoek in het kader van deze promotiestudie. Mede op basis van haar studie is het hoofdstuk "kosten-effectiviteit" in dit proefschrift geschreven. Een tweede met naam te vernoemen collega die vooral in de eindfase veel nuttig werk heeft geleverd is Jetske Verschuren. Zij kwam als een geschenk uit de hemel op het moment dat dossiergegevens verzameld en vervolgens ingevoerd moesten worden in databestanden. Vervolgens wil ik Christ Wesenbeek, Daan Schinning,

Bram Berkvens en Tom Joosten bedanken voor hun medewerking aan het verzamelen van onderzoeksdata in de rollen van ervaringsdeskundig en niet-ervaringsdeskundig interviewer. Mijn naaste collega's dank ik voor hun belangstelling, vertrouwen en het feit dat ze me "redelijk met rust hebben gelaten". Ten slotte ben ik GGzE erkentelijk voor de faciliteiten die me geboden zijn. Cliënten en hun mantelzorgers wil ik bedanken voor hun bereidwilligheid, altruïsme en openhartigheid bij het afnemen van interviews. Veel van hen participeerden in het onderzoek omwille van het veronderstelde nut voor cliënten die na hen nog te kampen zouden krijgen met psychosen. Jullie hebben me met al jullie verhalen overtuigd van het belang van goede zorg. Tevens hebben die contacten geresulteerd in een enorm respect en bewondering voor de kracht en weerbaarheid van patiënten en familie om steeds weer de vaak lastige herstel-weg te zoeken en op te gaan.

Een derde groep van mensen die ik dank verschuldigd ben, bestaat uit personen in de private sfeer, vrienden, vriendinnen, kennissen en familieleden. Hen wil ik niet alleen danken voor hun betrokkenheid en belangstelling maar vooral wil ik ook mijn excuses aanbieden voor de lange periode dat ik hen in meer of mindere mate verwaarloosd heb. Jullie hebben, ondanks mijn fysieke en/of mentale afwezigheid, steeds begrip opgebracht voor mijn situatie. Ik zeg jullie dan ook toe dat ik mijn best zal doen meer aandacht op te brengen voor jullie.

Een tweede dieptepunt in de afgelopen 4 jaren is het overlijden van mijn vader. Op een moment als dit is het gemis nog weer extra voelbaar. Ik had u er graag bij gehad, geen verstand van wetenschappelijke zaken, maar wel het hoogste woord. En vooral trots, want: "oze Giel dèh is Dokter!"

In het bijzonder wil ik natuurlijk mijn vrouw Rosita, onze kinderen Fleur en Guido en hond Rex noemen. Jullie hebben van nabij meegemaakt hoe onmogelijk ik me af en toe gedroeg en wat promotie-stress betekent voor de gezelligheid in huis. Meerdere malen bespraken we of dat wel opweegt tegen de opbrengsten van het onderzoek. Voor jou Rosita betekende dit dat je veel alleen moest doen en vaak alleen op pad moest. Naar de stad gaan winkelen was dan nog het minst een probleem. Alleen op vakantie, naar feestjes of gewoon wandelen in het bos gaf jou vaak het gevoel een pseudo-weduwe te zijn. Voor Fleur en Guido geldt dat er vaak sprake was van haast, geen tijd of geen zin om te voetballen, te kletsen, te computeren of hulp te bieden bij jullie huiswerk. Zonder jullie stimulerende aanwezigheid, geduld en begrip; de heerlijke maaltijden, kopjes koffie en in de avond nog een lekker wijntje, was het me niet gelukt de studie te volbrengen.

En ten slotte Rex: ook jou beloof ik dat ik weer meer aandacht ga schenken aan mijn rol als "family-man".

Curriculum Vitae

Giel Verhaegh is geboren op 3 december 1959 te Helden-Panningen. Hij heeft gedurende zijn carrière, werk en opleidingen regelmatig met elkaar verbonden. In 1979 startte hij als in-service leerling-verpleegkundige bij de toenmalige RPI in Eindhoven. Vervolgens werkte hij als verpleegkundig mentor en volgde hij de parttime Hogere Beroepsopleidingen: Inrichtingswerk aan de Hoge School te Eindhoven en Maatschappelijk Werk aan de Hoge School in Den Bosch. Vervolgens combineerde hij het praktijkwerk met een parttime post-HBO studie, de VO-Beroepsinnovatie, aan de Hoge School te Nijmegen. In 1996 behaalde hij zijn doctoraaltitel aan de Universiteit te Maastricht. Het afstudeeronderzoek was gewijd aan de tevredenheid van patiënten en hun familie met Psychiatrische Intensieve Thuiszorg. Hij zette naast de studie zijn praktijkwerk voort als beleidsmedewerker voor de Raad van Bestuur van Geïntegreerde Geestelijke Gezondheidszorg Eindhoven en de Kempen (GGzE). In deze rol (en later ook in de hoedanigheid van coördinator van het stafbureau van de Raad van Bestuur) werd hij belast met zorgvernieuwingsprojecten en samenwerkingsvraagstukken. Met naam te noemen beleidsspeerpunten waren zorgprogrammering, vermaatschappelijking en cliëntenparticipatie.
In 2004 was hij betrokken bij de start van Academische Werkplaats Geestdrift en vervult daar nog steeds de rol van coördinator vanuit GGzE. In het zelfde jaar startte hij met het promotie onderzoek naar de effecten van Assertive Community Treatment bij jonge patiënten met vroeg-psychose problematiek. De promotiestudie werd gecombineerd met beleidsmatig werk rond de ontwikkeling en implementatie van zorgprogramma's, (hoofd-)redacteurschap van het wetenschappelijk tijdschrift Metaforum en lid van de Wetenschapscommissie van de GGzE.

Giel Verhaegh was born in Helden-Panningen on the 3rd of December 1959. Throughout his career he has combined his professional activities (psychiatric nurse, nurse specialist, care innovator, and policy worker) with several lines of studies (psychiatric nurse, social work, healthcare innovations and health sciences).

In 2004 he started his PhD studies, as a science practitioner, at Tilburg University, department of Tranzo (Transformation of Care and Welfare). The studies included in this thesis address the effectiveness of an evidence-based treatment (Assertive Community Treatment: ACT) for patients suffering from early psychoses, in the Netherlands. The studies focus on treatment fidelity and model applications, client participation in research, (cost-) effectiveness, and the recovery process of patients suffering from an early psychosis.

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